

Aging and Developmental Disabilities I

895.34

THE NORTH DAKOTA STATEWIDE
DEVELOPMENTAL DISABILITIES
STAFF TRAINING PROGRAM

November, 2012



ACKNOWLEDGEMENTS

This training manual has been prepared through extensive use of the following training materials:

Aging and Developmental Disabilities - A Training Inservice Package: Indiana University, Institute for the Study of Developmental Disabilities and the Center on Aging and Aged.

Aging Process, Resource Center on Gerontology, University of North Dakota for Aging Services of North Dakota.

Amado, A.N., Conklin, F., & Wells, J. (1990) *Friends: A Manual for Connecting Persons with Disabilities and Community Members.* St. Paul, Minnesota: Human Services Research and Development Center.

Assessment, Resource Center on Gerontology, University of North Dakota for Aging Services of North Dakota.

Cotton, P. (1994). Retirement "to" something. In Conference Proceedings of the National Conference on Aging and Disabilities - A Vision For the Future, (pp. 87-96). Minot: North Dakota Center for Disabilities.

Developmental Disabilities and Alzheimer's Disease... What You Should Know (1995) developed by the Workgroup on Alzheimer's Disease and Developmental Disabilities and the New York Caregiver Assistance Project in Aging and Developmental Disabilities (New York State Office of Mental Retardation and Developmental Disabilities) and published by The Arc of the United States.

Fast Facts on Aging, (1992). University of Missouri-Kansas City Institute for Human Development, Kansas City, MO.

Gingold, W. & Sharff, A. (1981). *Geriatric Curriculum: Persistent Life Functions.* Fargo, ND: Red River Human Services Foundation.

Janicki, M. (1995). *Alzheimer's Disease and People with Mental Retardation.* Arlington, TX: The Arc.

Network of Trainers to Deliver Training to Personnel, Parents, Advocates, and Consumers in Aging and Developmental Disabilities, (1994) University of Central Oklahoma, Nigh Institute of State Government.

Mercer, M. (1996). *Supporting Older Adults with Developmental Disabilities to Access the Community.* (Available from North Dakota Center for Disabilities, Minot State University, 500 University Ave. W, Minot, ND 58707.

Rinck, C. (1992). Physical changes as persons with developmental disabilities age. *Fast Facts on Aging*. U.M.K.C. Institute for Human Development, University of Missouri - Kansas City.

Rinck, C. (1992). Program Planning for older persons with developmental disabilities. *Fast Facts on Aging*. U.M.K.C. Institute for Human Development, University of Missouri - Kansas City.

Rinck, C. (1993). Assessment for choosing work or retirement options training guide for aging specialists. *Fast Facts on Aging*. U.M.K.C. Institute for Human Development, University of Missouri - Kansas City.

The Wit to Win: How to Integrate Older Persons with Developmental Disabilities into Community Aging Programs, New York State Office for the Aging.

The Department of Human Services, Developmental Disabilities Division, and Minot State University wish to thank all who contributed to the development of the first edition of the training manual. Special thanks to Peggy Lutovsky, Teresa Larson, Carol Neumiller Brakel, Demetrios Vassiliou, and Elizabeth Olday.

1996 revisions and additions: Mary Mercer, North Dakota Center for Persons with Disabilities, a University Affiliated Program at Minot State University, Minot, ND.

TABLE OF CONTENTS

Page

Aging and Developmental Disabilities I (Module 895.34)

Module I: Introduction and Overview

Unit I: Population Overview	1
Unit II: Philosophical Considerations.....	9

Module II: Medical and Health Issues

Unit III: Health Promotion	19
Unit IV: Developmental Disabilities and Alzheimer's Disease.....	41
Unit V: Aging and Cerebral Palsy: Clinical Concerns	53
Unit VI: Mental Health Issues	63

Module III: Legal Services

Unit VII: Rights	75
Unit VIII: Abuse, Neglect and Exploitation	92

Feedback Answer Key	97
----------------------------------	-----------

MODULE I: INTRODUCTION AND OVERVIEW

UNIT I POPULATION OVERVIEW

OBJECTIVES: After completing this unit, staff members should be able to:

Describe why it is difficult to establish a chronological age that identifies the point at which individuals with intellectual disabilities begin showing signs of aging.

Explain why estimates of the number of persons with developmental disabilities who are aging are probably low.

List the major demographic characteristics of elderly people with developmental disabilities.

List the major health and functional characteristics of persons with developmental disabilities who are aging.

INTRODUCTION

America's population is aging. This growth is often referred to as the graying of America. Society as a whole has become aware of the growing number of elderly people needing specialized services. What is perhaps less obvious, is the increasing number of people with developmental disabilities who are aging.



Definitions of Terms Related To Aging

In the United States, legislative and administrative policies define "old age" in various ways. The Social Security Act defines age 65 as a beginning point of entitlement for the collection of old age and retirement benefits. However, the Older Americans Act designates age 60 as the base age for eligibility for a variety of social and support services. Further, prior to the legislative prohibition of most mandatory retirement policies, age 65 or 70 was often used by employers as the age for mandatory retirement.

Studies of the general elderly population reveal a similar lack of consensus with respect to definitions of old age. Gerontologists, who study aging from a psychological; socio-economical; physiological; historical; and clinical perspective, have divided "old age" into several categories. The young-old are between the ages of 65-74 years of age. The old are described as being 75-84 years of age, and the oldest old are 85+ years of age. It is the oldest old which is the fastest growing segment of the population.

Definitions of Developmental Disabilities

Unlike the terms elderly, aged, or aging, the term "developmental disability" is not a part of everyday speech for most people. It is a legal definition which was established by Congress in 1970. Its more recent application was given in the Developmental Disabilities

Assistance and Bill of Rights Act of 1990 (Public Law 101-496), which gives the federal definition of a developmental disability as:

a severe, chronic disability of a person 5 years of age or older which--

- (a) is attributable to a mental or physical impairment or combination of mental and physical impairments;
- (b) is manifested before the person attains age twenty-two;
- (c) is likely to continue indefinitely;
- (d) results in substantial functional limitations in three or more of the following areas of major life activity:
 - self-care
 - receptive and expressive language
 - learning
 - mobility
 - self-direction
 - capacity for independent living, and
 - economic self-sufficiency; and
- (e) reflects the person's need for a combination and sequence of special interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated; except that such term, when applied to infants and young children means individuals from birth to age 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.

The North Dakota Legislature and Department of Human Services have adopted the federal definition of "developmental disability." This definition is obviously not concerned with a clinical diagnosis or etiology (cause) of a condition; it simply establishes: **1) criteria of onset, 2) duration, and 3) impairment of functions essential to personal independence.**

Applying Definitions of Aging to Individuals with Disabilities

Many difficulties arise from applying definitions or perceptions of aging/ old age to individuals with developmental disabilities. First, in the general elderly population, individuals are not considered to be aging until they are in their 60s and 70s, and not truly old until they are in their 80s. However, because of historically shorter lifespan and instances of premature aging of individuals with developmental disabilities, such individuals are often considered elderly in their 50s.

Also, there is a lack of consensus among developmental disabilities professionals as to what age constitutes the beginning of old age for this group. An examination of published research studies and reports has shown the definition of "old age" for this population to range between 40 and 75 years of age (Seltzer & Krauss, 1987). Ages used by public

agencies show similar variability; a survey of state developmental disabilities planning councils and state units on aging found that ages in use ranged from age 55 to 65 (Janicki, Ackerman & Jacobson,1985).

Reasons for the widely varying definitions of old age among individuals with developmental disabilities include:

1. some individuals with intellectual disabilities begin to experience decline in behavioral capabilities in their 50s (Hewitt, Fenner, & Torpy,1986; Janicki & Jacobson,1986),
2. there is evidence of premature physical aging (along with an increased incidence of Alzheimer's disease) among persons with Down syndrome -- a major subgroup within the population of persons with intellectual disabilities (Lott & Lai,1982; Miniszek,1983; Wisniewski & Merz,1985), and
3. persons with intellectual disabilities have historically had a shorter average lifespan than the general population (Jancar, 1986; Richards, 1969; Tarjan, Wright, Eyman, & Keeran, 1973).

Individuals with developmental disabilities may age in different ways with respect to each of the three trends noted above. Persons with mild or moderate intellectual disabilities may have very different social, educational, medical, and functional characteristics, and service histories, from those with severe or profound intellectual disabilities (Janicki & Jacobson, 1986; Lakin, 1985).

Similarly, individuals with intellectual disabilities who are without additional physical handicaps differ from those who have an organic basis for their intellectual disability. Individuals with severe intellectual disabilities and multiple disabilities are expected to have a shorter life expectancy. The characteristics of these groups influence the aging process making it impossible to describe a common pattern of aging among all individuals with intellectual disabilities.

Further, what is known about the definition of old age is limited because studies conducted with aging or elderly populations of adults with intellectual disabilities usually:

1. involve limited or selected populations--such as studies of individuals with Down syndrome to examine the factors associated with premature aging or Alzheimer's disease;
2. involve individuals who are known to formal service providing agencies and, consequently, are not a representative sample of all older individuals with intellectual disabilities; and
3. do not use control groups of non-retarded age peers to isolate the true age effects from differences solely attributable to the intellectual disabilities.

The inclusion of specific provisions for older Americans with disabilities in the 1987 reauthorization of the Older Americans Act of 1965 may eventually lead to a common definition (Rose & Janicki, 1986). The Act specifies age 60 as the age of eligibility for services and requires equal access to services by older Americans with disabilities. However, the problems posed by individuals with intellectual disabilities who age prematurely will still necessitate the use of a younger age (possibly 55) for definitional purposes and provision of services. It is evident that a consistent definition is needed to improve communication, promote data uniformity, and enhance program development.

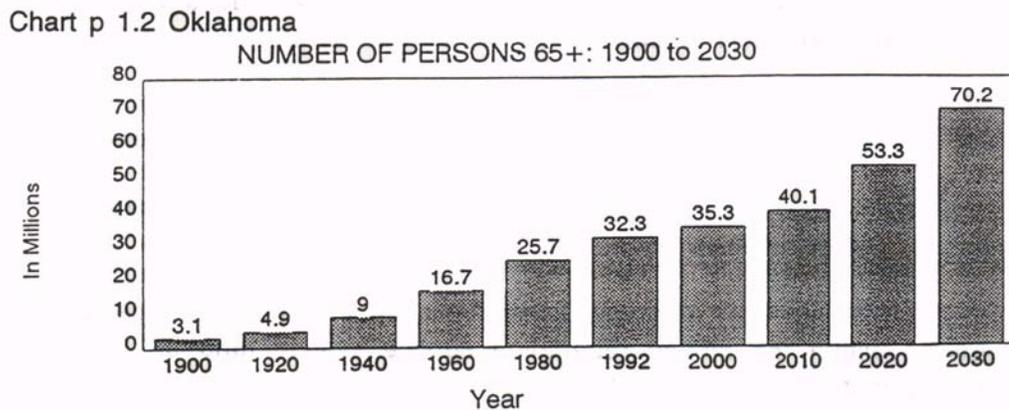
DEMOGRAPHICS

Demography is the scientific study of changes in the characteristics of a population. When looking at the elderly in particular, not only are the numbers of people over the age of 65 increasing, but changes are also occurring in health status of this group. People are living longer, healthier, more active lives. However, increased life expectancy brings with it new problems.

Older Americans

Numbers. There were 31.2 million persons who were over the age of 65 in 1990. This equates to 12.6% of the total population and reflects a growth of 22% since 1980. If this current growth rate continues, we can expect by the year 2010, 1 out of every 7 Americans will be elderly.

Chart p 1.2 Oklahoma



Health Status. About 23% of older people, or 6.1 million, living in the community have health-related difficulties with one or more personal care activities (bathing, dressing, eating, walking, using toilet). People over 65 average eight doctor visits annually. In 1992, \$100 billion was spent on Medicare and Medicaid. Older people consume twice as much medication as all other age groups and occupy 40% of the nation's hospital beds. Most older Americans have at least one chronic condition and many have multiple conditions. The most common conditions are: arthritis (48%), hypertension (37%), hearing impairments (32%), heart disease (30%), orthopedic impairments (18%), and cataracts (17%).

Life Expectancy. In the past 90 years, we have added 30 years to the average life expectancy. Life expectancy has increased from about 47 in 1900 to 72 for males and 79 for females in 1990. In the past, death would have been rather sudden and the result of an accident or acute illness, while today death usually occurs after a chronic lingering illness.

Older Persons With Developmental Disabilities

Numbers. There are an estimated 173,000 adults age 60 and older with intellectual disabilities and other developmental disabilities (e.g. cerebral palsy, autism, epilepsy)(Rehabilitation Research and Training Center on Aging with Mental Retardation, 1995). A number of factors affect the accurate determination of the number of older Americans with intellectual disabilities/developmental disabilities. These include:

1. the difficulty of distinguishing between older adults who have cognitive or functional impairments and older adults who have intellectual disabilities;
2. the disassociation of some older Americans from the formal intellectual disabilities service system (the "unknown" group); and
3. at old age, the lack of a need to label people by disability type to obtain services generally available to any older person.

Consequently, general estimates based upon data on persons receiving services within the intellectual disabilities service system tend to underestimate the true size of this group.

It is estimated that the population of individuals age 60+ with intellectual disabilities/developmental disabilities will nearly double to 332,900 by 2025 because of longevity and size of the post World War II "baby boom" generation born between 1946-1964. If these data are indicative of trends in other states, the number of older individuals with intellectual disabilities/developmental disabilities will increase dramatically across the nation and in North Dakota.

Demographic Characteristics. It has been noted that during their 50s and 60s, men outnumber women by about 52% to 48%. By the time they reach their 80s, women outnumber men by about three to one (Janicki & Jacobson,1986). With advancing age, the differences between men and women with regard to presence of chronic physical conditions become more apparent, particularly in problems present in the cardiovascular, genitourinary, and endocrine systems (Janicki & Jacobson,1986).

Health and Functional Characteristics. It is generally assumed that older adults with intellectual disabilities have more health impairments and functional limitations than younger adults. However, studies on the health status of this group have reported conflicting results. Access to health services has been noted to be a function of the living

environment--older Americans in group homes had the most frequent contact with physicians, followed by those in foster family care and then by those living with their natural families (Janicki, Ackerman, & Jacobson, 1985). It has also been reported that longevity was greater among those individuals whose intellectual disabilities did not have a genetic etiology (Forssman & Akesson, 1965) and who have not experienced lengthy institutionalization (Lubin & Kiely, 1985; Tait, 1983).



In terms of functional limitations, studies of different samples have yielded conflicting outcomes. Among individuals with mild and moderate intellectual disability, declining abilities in motor skills and in activities of daily living were not observed until the mid-70s (Janicki & Jacobson, 1986). The decline was not as great in individuals with severe and profound intellectual disability, due to the fewer initial skills compared to individuals with mild and moderate intellectual disability.

In a recently reported study of about 60,000 individuals with developmental disabilities in California, lifelong increments in adaptive behavior were found for residents in community-based settings (Eyman & Widaman, 1987).

Behavioral skill decline patterns among older Americans with intellectual disabilities indicate that a few skills (such as gross motor functioning and some performance measures) show decline early in the aging process, while most other skills do not show decline until much later (Bell & Zubek, 1960; Hewitt, Fenner, & Torpy, 1986; Janicki & Jacobson, 1986). It has also been reported that older Americans in the community are more behaviorally, physically, and intellectually capable than are their age peers living in institutional settings (Anderson et al., 1987; Janicki, 1986a; Krauss & Seltzer, 1986).

Studies of changes in intellectual capabilities indicate that older individuals with intellectual disabilities show ongoing intellectual development until late middle-age, with intellectual decline not usually observed until after the mid-60s (Eyman & Widaman, 1987; Hewitt et al., 1986). In addition, although early onset of aging is prevalent among persons with certain conditions, in particular those with Down Syndrome, this is not necessarily true for all older Americans with intellectual disabilities (Reid & Aungle, 1974; Wisniewski & Merz, 1985; Zigman, Schupf, Lubin & Silverman, 1987). There is also evidence that senile dementia may begin at a relatively early age (i.e., in the 40s) among those individuals with Down Syndrome (Reid & Aungle, 1974).

The findings of these studies point to the need for more research into the health, functional, and behavioral characteristics of individuals with intellectual disabilities in old age. It is undoubtedly the case that some of the inconsistencies noted above are a result of unique subgroups of individuals with intellectual disabilities included in the various samples studied. In addition, longitudinal and cross-sectional designs often reveal different patterns (see Seltzer, 1985a).

CONCLUSION

This unit has focused on three questions which are central to planning and services for older/elderly Americans with intellectual disabilities and other developmental disabilities.

The first question examined various ways in which "aging" and "old age" can be defined for the general population and the applicability of these definitions for persons with intellectual disabilities. Although a chronologically based definition is appealing for its administrative simplicity, some characteristics of persons with intellectual disabilities make the designation of a fixed age marker problematic.

Nevertheless, given the prevalence of age-based eligibility criteria for federal and state funded programs, it is likely that either the existing age criteria will be applied to populations with lifelong disabilities, such as intellectual disabilities, or that a slightly lower age criterion will be designated for "special" populations whose atypical aging patterns warrant such modifications. Although age 55 is the most commonly used age point for denoting "elderly" in the intellectual disabilities literature, the use of 60 is increasing as there is greater awareness of the Older Americans Act provision on disability. However, no consensus currently exists among professionals regarding the most appropriate chronological demarcation.

The second question examined the issue of size of the older/elderly population with intellectual disabilities. It is clear that estimates based on persons "known" to the service system substantially underestimate the true size of this group and that the size of the population will significantly increase over the next 20-30 years.

The third question focused on the demographic, functional, health and social support characteristics of older/elderly persons with intellectual disabilities. Atypical aging patterns for particular subgroups of this population were noted. Future research should examine whether successive generations will show more similarities with the general population.

Findings indicate that individual sub-groups within the population of elderly persons with intellectual disabilities vary with respect to their health and functional characteristics. Further, there is evidence that some early loss of functional skills does occur in this population; however, the loss is variable and subject to influences such as level of impairment, health status, and length of institutionalization.

FEEDBACK EXERCISE I

1. What are some reasons for the widely varying base age for defining old age among individuals with intellectual disabilities and other developmental disabilities? List at least three reasons.
2. Name three factors which affect the accurate determination of the number of older Americans with intellectual disabilities.
3. Compare the demographics of the aging population with the demographics of the population of individuals with developmental disabilities who are aging.

UNIT II: PHILOSOPHICAL CONSIDERATIONS

OBJECTIVES: After completing this unit, staff members will be able to:

Define the normalization principle.

Define social role valorization.

Identify five major components of the normalization principle.

Define "double jeopardy" with respect to aging persons with D.D.

Define the developmental principle.

Identify developmentally appropriate alternatives for active treatment of older persons with D.D.

ROLE OF PHILOSOPHY IN SERVICE DELIVERY

In a set of training materials which claims to have a practical purpose of training practitioners, why have a unit on philosophy? What do we mean by philosophy anyway? What are philosophical issues related to older people with developmental disabilities? Philosophy is used in this unit as "a system of motivating concepts or principles" (Morris, 1969). We are concerned with the principles which underlie the delivery of human services to older persons who have lifelong disabilities. This philosophy includes the expression of values, principles, or qualities considered desirable in dealing with older adults with developmental disabilities. Such principles are derived from the collected opinions of experts in the field. They provide guidelines for those of us by which we may judge the quality of services which we provide.



In considering the philosophy underlying the delivery of human services to older persons with disabilities, there are two domains which must be interwoven--that relating to treatment of persons with developmental disabilities and that relating to treatment of older persons in general.

Attitudes Towards Persons with Developmental Disabilities

Persons with developmental disabilities face more problems than those created by their disabilities. The effects of their disability are compounded by the reaction of others, their own diminished experiences, and personal perceptions of being devalued as members of society. They are seen as being "different" by others. While some people are overly sympathetic and too helpful, others may stare or make fun of them. Because some

persons with disabilities experience rejection over and over, they may have great difficulty meeting others and may lack appropriate social behavior. It is difficult to form relationships when there are few opportunities for contacts with others.

Many persons with developmental disabilities have been isolated in their own homes or institutions. Their day is regulated by others and they do not learn to make decisions about their own lives causing a lack of self confidence. Until the advent of sheltered workshops, employment was nonexistent for them. Experiences of people with disabilities are limited both by their condition and by society's provisions for them.

Much has been done in the last few years to guarantee certain rights of people with disabilities. Focus has been placed on the accessibility of public buildings, providing employment opportunities, and expanding social services for people with developmental disabilities. The media has attempted to advance the image of people who have developmental disabilities by including them in commercials, movies, and television series by portraying them as productive members of society. Even though we are in the process of changing the negative stereotype that many people have of persons with disabilities, they still face attitudinal barriers.

Myths and Stereotypes of the Elderly

A myth is a belief based on something other than the systematic study of the matter. While all myths are not necessarily incorrect, they are usually distorted. Beliefs about older people often lead to stereotyping the elderly as forgetful, uninteresting, and incompetent. This in turn can lead to a self-fulfilling prophecy for the elderly who may then refuse to learn a new skill because they believe themselves incapable. Often a treatable disease may be ignored because it is perceived as a normal process of aging. The older person may avoid social interaction because of a lack of self esteem or feelings of worthlessness. Older people may feel they have nothing to offer or contribute.

Negative stereotypes and acceptance of myths of aging can lead to discrimination against the elderly simply because of their age. This is referred to as **ageism**. Ageism can be found in the use of such derogatory terms as "fossil", "old geezer", "grump", "old foggy", or "coot". Ageism can result in job discrimination or inadequate health care for the elderly. Health practitioners in general assign lower priority to service to the elderly than to any other age group.

Double Jeopardy. Some authors believe that society has segregated and devalued older people to a worse degree than disabled persons (Schalock & Lilley, 1983). When a person is both old and disabled, he/she can be said to be in "double jeopardy" (Dickerson, Hamilton, Hauber, & Segal, 1979).

Triple Jeopardy. More recently, Rowitz (1987) pointed out that "triple jeopardy" may be more characteristic of this population, since most suffer from economic impoverishment as well. Thus, the issues involved in planning and delivering services to older persons who also have lifelong disabilities have to address a more complex set of societal attitudes than for either the younger population with disabilities or the generic aging population.

NORMALIZATION AND SOCIAL ROLE VALORIZATION

The basic principle underlying the delivery of services to those with developmental disabilities is the principle of normalization, now called social role valorization. This unit presents an explanation of the principle of normalization, and of social role valorization, and how they may be applied to human services in general and specifically to the aging and aged population who have developmental disabilities.

Normalization is defined as "the utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible" (Wolfensburger, 1972 p. 28). Another way to describe normalization is "the process of assisting the individual to acquire behaviors and characteristics typical of their culture."

After much debate in the literature, which centered around questions such as whether this meant striving to make everybody just alike, or striving to make people with handicaps normal, or striving to make them do "what most people do" rather than "what society rewards people for doing," Wolfensburger (1983) proposed a new term for the principle of normalization--*social role valorization*.

"Social Role Valorization . . . has as its primary goal the establishment and protection of positively valued social roles for people who are devalued by society or at risk of devaluation" (Wolfensburger, 1985, p. 61).

Thus, the ultimate goal of human services under this philosophy is social role enhancement or maintenance for persons served.

Although the two terms continue to appear in the literature, there is concern that "normalization" suggests that whatever we do for "normal" older people ought to be done for older persons with developmental disabilities. Since considerable discrimination against the aged exists in American society, this assumption might lead to continued or even greater discrimination against aged persons with developmental disabilities. To treat the aged individual with disabilities just as we treat the aged in general in our society is certainly not an ideal goal, since both groups have suffered devaluation by society.

Stigmatization

People with developmental disabilities, and particularly those with intellectual disabilities, have been stigmatized and are not fully accepted American society. If the role definition imposed on a person is a negative one (such as handicapped person or aged person), that person has been "devalued." People may be devalued because of the way they look, how they behave, or because of race, color, or creed. This devalued status is not due to something within the person; "it is within the imposed social roles, the values and the perceivers' interpretation" (Wolfensburger, 1980, p. 13).

Gardner and Chapman (1985) write about the combination of being different and being devalued by society:

The distinction between the terms different and devalued is important. Many individuals are different but not devalued. The late Howard Hughes or Hugh Hefner, for example, may have acted or act very differently from most people. They have not, however, been devalued . . . If you are valued and accepted . . . you can deviate from the norm in certain ways . . . However, people who have mental retardation and are devalued are not allowed to act differently.
(p. 21)

Behavior from a socially valued person that would be tolerated, such as talking too loudly in a restaurant, is less likely to be tolerated from a person with intellectual disabilities. That person must act in a more conservative manner in order to attain societal acceptance. Both the normalization principle and the concept of social role valorization suggest that employees of human service agencies should minimize the perceived differentness of people with developmental disabilities. Providers of services should seek to reduce stigma and deviancy associated with developmental disabilities.

Social role valorization may prevent devaluation and maltreatment by:

1. reducing or preventing the differences that may cause a person to become devalued in the eyes of observers; and/or
2. changing other people's perceptions and values in regard to a particular characteristic or condition, so that special or different people are no longer seen as devalued (Wolfensburger, 1985).

These two goals can be pursued through the two major avenues of (a) the enhancement of the social image of the person or group, and (b) the enhancement of the competencies of the persons or group. These need to be accomplished by the use of "culturally valued means." "Both the means to the end and the end behavior or experience should be valued and typical of the norm." (Garner & Chapman, 1985, p 21.) Nirje (1980) writes about three aspects of intellectual disabilities (which are applicable to other developmental disabilities as well):

1. the intellectual disabilities of the individual, which is the actual cognitive and behavioral deficit;
2. the imposed or acquired disability, which is caused by the environment provided to the person and by societal attitudes; and
3. the awareness of having a disability

The second aspect in Nirje's list is caused by deficiencies in the environment or life of the person created by society. "Institutional poverty, nonexistent or unsatisfactory education or vocational training, lack of experiences and social contacts, the problems of understanding

society, all add to the original handicap. However, all these things are amenable to change and can lessen the impact on the individual of the actual retardation and the awareness of retardation” (Nirje, 1980, p32). As indicated above, the same principles also apply to developmental disabilities other than intellectual disabilities.

Implications for Service Delivery

The normalization principle has a variety of implications for the delivery of human service to persons with developmental disabilities. These implications can be divided into (a) service outcomes and (b) service methods. **Outcomes** include things like the skills, abilities, and behaviors of people with developmental disabilities; the quality of life which they experience in residential, vocational, and leisure activities; and the public perception of this population.

The normalization principle is also very much concerned with **service methods** or how human service agencies achieve these outcomes. A program, for example, might be successful at enhancing skills but give a **message to the public** that persons with developmental disabilities who participate in this program are devalued or dependent. A vocational program, for instance, might be successful at teaching new skills, but if it is housed in an old rundown building in a questionable part of town and the trainees are all bussed in together in a bus which says "Retardation Center" or "Vocational Special Needs" on the side, the methods are not in accordance with either normalization or social role valorization.

The language used to describe people also sends messages both to the person and to the public. An older person with disabilities is first of all a person. He/she is not a "retard," a "mongoloid," a "CP," or an "oldie," but a person who has intellectual disability or cerebral palsy or who is older.

Another implication of the normalization principle is that persons with developmental disabilities should be treated in an age-appropriate manner. Historically people with developmental disabilities, particularly intellectual disabilities, have been perceived as childlike, or "never growing up". One reason is the misunderstanding of a person's mental age as derived from some intelligence tests. However, having a mental or developmental age of 5 years when one is chronologically 60 years old does not mean that the person is like a 5 year-old. Treating a sixty year old like a five year old is demeaning and never appropriate.

Age appropriateness means treating a person with a disability as you would treat any person of the same chronological age. Your interactions should be based on a fundamental respect for the person.

- Offer the person choices that others his/her age would consider.
- Address the older person with a disability as you would any other older person.
- Provide assistance in a manner that allows for maximum independence

The following chart gives some examples of age appropriate and age-inappropriate behaviors and responses.

Situation	Age-inappropriate activities or responses (fosters childlike image)	Age-appropriate activities or suggested response
Nicknames	Tommy, Billie	Tom, Bill
McDonald's counter	Companion ordering for the person who doesn't speak.	The person shows a picture of a cheeseburger and fries to the server
Going to a movie	Seeing a cartoon or children's show	Seeing a western, suspense, or drama
Eating a meal family style	Saying, "Eat your vegetables!"	Asking, "Do you want some broccoli?"
Shopping for clothing	Companion selects and pays for the purchase for the person with a disability.	The person chooses what they want to buy and pays for the item with their own money.
Hobbies	Coloring in children's coloring book, playing Candyland, watching Sesame Street	Art project with felt tip markers or paints, fishing, playing Bingo, making recycled greeting cards, watching sports
Tone of voice, speech	Higher pitch, baby talk	Normal tone and words the person understands

INDIVIDUALIZATION

The philosophy underlying services to the elderly has been stated by one expert as follows: "A guiding philosophy of services to the aging is to assure that their provision supports the individualized and unique needs and capabilities of the older person" (Beattie, 1976). For older persons, the guiding notion involves maintaining as much independence as possible while keeping in mind the importance of self-determination and choice of service alternatives.

LEAST RESTRICTIVE ALTERNATIVE AND SELF-DETERMINATION

The principle of normalization applies to both the aging and the developmental disabilities sides of the "double jeopardy" issue, especially when it is accompanied by the concepts of least restrictive alternative and self-determination. People have a right to self-determination of their own lives. This includes the right to choose services and to refuse services. Staff members in human service agencies have no authority to do anything to or for a person without that person's consent or, if the person is not competent to give consent, the consent of his/her legal guardian. (See the Legal Services unit for issues of informed consent). Furthermore human service providers are expected to adhere to the concept of least restrictive alternative, which means that services, programs, and life situations should be

provided in the most typical setting possible while still meeting the person's needs. In addition, provision of more services than are actually needed can foster unnecessary dependence.

THE DEVELOPMENTAL PRINCIPLE WITH OLDER ADULTS WHO HAVE DEVELOPMENTAL DISABILITIES

Another guiding principle for human services is the developmental principle. It states that every person, no matter how severely handicapped, has the capacity to learn, grow, and develop throughout life. The role of the human service system is to develop services that will minimize the degree of disability and provide the necessary supports to open up most if not all of life's options to people with disabilities.

In earlier life stages it is clear that active, aggressive developmental programming geared toward the development of increasingly complex skills is appropriate. In later life stages the appropriateness of this goal becomes less clear. Should the development of new skills, particularly employment-related skills, be an essential part of older adult programming?

Developmental psychologist Robert Havighurst (1971) lays out what he believes to be the developmental tasks we need to accomplish throughout the lifespan. Developmental tasks of later maturity, are as follows:

1. Adjusting to decreasing physical strength and health. While some aspects of physical functioning can be maintained through healthy lifestyles, some degree of physical decline is inevitable and we have to learn to adjust to changes such as decreased visual and auditory acuity (keenness), stiffening joints, and lowered vital capacity.
2. Adjustment to retirement and reduced income. There is increasing evidence that this is a positive adjustment for the majority of retired workers. Increased leisure time could lead to increased development of leisure skills for adults with developmental disabilities.
3. Adjusting to death of spouse (or other significant persons in one's life), which certainly applies to older persons with developmental disabilities as well as older persons in general.
4. Establishing an explicit affiliation with one's age group.
5. Adopting and adapting social roles in a flexible way-- that is, adjusting to the loss of a spouse or the ability to work with other satisfying roles such as volunteer in the community, church member, friend, or bowling team member.
6. Establishing satisfactory physical living arrangements.

Thus, the notion that developmental programming should continue to push for more and more complex, and often job-related, skills has less application when you consider late-life

development. The tasks listed above are more age-appropriate. Old age is a time for consolidation and maintenance of skills already attained with increased opportunity to apply them (particularly social skills) in leisure activities. Perhaps, for an older person, objectives should focus on greater responsibility and enjoyment in their current living environment as opposed to learning skills for some later, less restrictive apartment living. Attention to age-appropriate tasks also highlights the important role that case managers and others in aging services can play in developing appropriate programming for seniors with developmental disabilities.

CRITERIA OF NORMALIZATION

When service systems are analyzed to determine to what extent they are adhering to the principle of normalization, most of the major criteria can be grouped under the following five headings (Gardner & Chapman, 1985):

1. Community Presence. This criterion says that both the programs for persons with disabilities and the persons themselves should be situated in the community in close proximity to needed goods and services and to other people.
2. Community Participation. This criterion is a measure of the extent to which people are socially integrated into the community. Social integration involves both personal and impersonal (such as with salespeople) interactions. Community participation is increased by use of generic services such as senior centers, the public library, or local recreation facilities. If these facilities have not previously served persons with disabilities, they may need to be assisted in meeting their needs, but they have a responsibility to serve all citizens. The urge to always develop separate, isolated services for those with disabilities should be suppressed, however, since isolation does not lead to community participation, which in turn will not facilitate social role valorization.
3. Skill Enhancement. The third criterion for normalization says that people should perform according to their culture's expectations for a particular age range. Physical and social overprotection are to be avoided. People should be exposed to normative dangers, risks, and learning challenges. We learn by making a series of mistakes. Overprotection keeps us from learning. Of course, regular safety measures such as fire drills, smoke alarms, grab bars for older persons, railings on stairways, and proper lighting in hallways are appropriate.
4. Status Enhancement. This involves the consideration that the public perception of human service programs is as important as what the programs accomplish. Because some people are treated as they are perceived, it is important to see that they are perceived positively. In addition, a person who is perceived positively will start to act in accordance with those positive perceptions (self-fulfilling prophecy). Thus, adults who have developmental disabilities should dress in adult fashion and not carry cartoon character lunch boxes to work. They should not be transported in yellow school buses that say "Special Education" or "Intellectual disabilities Services" on the side. Age-appropriate forms of address should be used.

5. Autonomy and Empowerment The final criterion for normalization means transferring power and control to the person with disabilities. As has previously been discussed under self-determination, the responsibility for making decisions rests with the person with developmental disabilities. The responsibility of staff is to teach and assist people with disabilities to make responsible decisions for themselves to the greatest extent possible.

Further information concerning evaluation of service systems can be found in *PASSING: Program Analysis of Service Systems' Implementation of Normalization Goals: Normalization Criteria and Rating Manual* 2nd ed. by Wolfensburger and Thomas (1983).

THE NORMALIZATION PRINCIPLE AND REALITY

Some people argue that normalization is totally unrealistic. Surely the principle is idealistic. It states how services **should** be provided, not how they **are** provided. It gives a goal to strive for, not a reality that can be reached at all times. Sometimes the range of alternatives that can be offered is restricted. Then the individual should be assisted to make the best choice he/she can. Service providers are responsible to push for program change. By setting goals high, agencies will not be satisfied with inferior services, even when that is the best that can be provided at the moment. Such striving brings about growth in the service system, as well as for the recipients of services.

CONCLUSION

Service providers who understand and adopt the principles outlined in this chapter will be better prepared to evaluate proposed changes in the service delivery system. Positive growth will stop if changes do not rest on a value-based foundation. Without a sound and useful philosophy to adhere to, we are left to passively accept prevalent attitudes towards the elderly and those with developmental disabilities as they are presented to us by our society.

FEEDBACK EXERCISE II

1. What is Normalization?
2. Define Social Role Valorization
3. What three factors place an older person with developmental disabilities in “triple jeopardy”?
4. List and explain the five criteria presented in this Unit which must be present in programs in order to adhere to the Principle of Normalization.
5. What is the role of philosophy in service delivery?
6. Define the term “ageism”:
7. Give an example of age appropriate treatment of an older person with a developmental disability.
8. Define the developmental principle.
9. Identify developmentally appropriate alternatives for active treatment of older persons with D.D.
10. What does the term “individualization” mean in delivery of services to older adults?
11. Apply the term “least restrictive alternative” to delivery of services to older adults?

MODULE II: MEDICAL AND HEALTH ISSUES

UNIT III: HEALTH PROMOTION

OBJECTIVES: After completing this unit, staff members will be able to:

List several ways in helping elderly individuals with developmental disabilities establish and maintain healthy patterns of living.

Explain many physiological changes (vision, hearing, etc.) which occur as a result of the aging process, understand the implications and provide suggestions for compensation.

HEALTH AND WELL BEING



When we speak of health and well-being, we refer to more than just the absence of disease. We refer to physical vigor, strength, endurance, flexibility, and grace. In addition, physical well-being is only one element of the picture, total well-being encompasses our emotional, social, cognitive, and spiritual states. One way to assess health and well-being is to consider a person's skills and abilities to complete the activities of daily living.

When working with older people, we must recognize that old age can be a time of fragility and loss of reserve. Age related changes are not the same as or necessarily the result of illness or injury.

They are the natural and expected processes of aging. However, we also know that the loss of functional capacity among the elderly can be increased by the lack of activity and good medical care. The old adage "Use it or lose it" is true. To provide services to older people in a way that promotes health and well-being (from ADDTIP):

1. Don't assume that old necessarily means a rapid and invariable downhill course.
2. Make frequent functional assessment, being careful to recognize and rejoice when there is no loss of function.
3. Don't push the person to attain skills or abilities beyond his/her capabilities. However, remember that everyone can learn some new skills and abilities.
4. Remember that skills must be used to be retained.
5. Don't be overprotective. Allow the person to do things for themselves, so you don't rob them of the opportunity to practice what they are capable of doing.

As indicated above, many physiological changes occur as we age. These changes occur in the general population as well as among people with developmental disabilities. Some of these changes are described in the following pages.

VISION

Changes

Changes in vision, attributed to age, begin to occur during the 40s. At the age of 80 years, 90% of elderly have some form of visual impairment. As a person ages, there are many physical changes in the eyeball and accompanying structures. The lenses change by yellowing, having decreased flexibility, and changing shape. There is also a decrease of natural lubrication in the eyes, and the muscles change. There is an increased incidence of glaucoma and cataracts.



Types of Impairment	Causes/Effects
Presbyopia, or farsightedness	Words closer than 12" become difficult to read. Usually corrected by the use of glasses.
Decline in visual clarity or sharpness	Objects appear less clear. Both farsightedness and decline in clarity occur as the lens of the eye becomes less flexible.
Change in color perception	Colors such as blue and violet, at the lower end of the color spectrum, are difficult to see because the eye's lens begin to yellow. Colors of yellow, orange and red are easier to see. Shapes and boundaries are harder to distinguish.
Decrease of sharpness of vision	Occurs in situations of low light. Higher degrees of illumination are needed.
Sensitivity to light	The older person may experience problems with glare or have difficulty adapting to changes of light levels.
Dry Eyes	Eyes itch and burn because they are not getting enough tears from the tear glands.
Excessive Tears	Eyes have an increased sensitivity to wind, light or temperature changes.
Floaters	Tiny spots or specks that one can see moving across the field of vision.
Cataracts	Occur when the lens becomes opaque or clouded. When light hits the eye it produces a glare and reduced vision.
Senile macular degeneration	A degeneration of the macular area of the retina which results in a loss of central vision.
Glaucoma and Diabetes	Both conditions can result in blindness. An early sign of glaucoma may be a halo seen around sources of light.

Detecting a Visual Impairment:

Frequently, the older adult will openly share concerns about their vision. In other cases, if the changes occurred slowly the individual may have adapted to the point that they are unaware of the impairment. Some individuals may be unable or unwilling to discuss the loss with anyone. Listed below are cues that may be used to detect visual impairment:

1. Spotted, soiled or mismatched clothing.
2. Heavy use of non-visuals such as searching with their hands for an object, or searching for the edge of a chair to walk around it.
3. Intense lighting.
4. The person consistently sits nearest to the direct source of light.
5. Accidents or falls.
6. Decline in cleanliness of living area.

Implications:

As a result of these changes, older persons may find close work burdensome. They may get headaches and eye strain. They may find new environments threatening, because of poor depth perception, far vision, or the ability to distinguish details. They may have a fear of falling or of steps because of the lack of depth perception and the ability to distinguish changes in the surface they are walking on. Boredom, depression, feelings of dependency, and fear of total blindness are often serious concerns for those experiencing visual impairment.

Suggestions:

There are many ways that we can help older people compensate for changes in their vision.

1. Use bright contrasting colors around doors and steps.
2. Avoid highly polished surfaces. This will allow for good illumination, yet limit the glare.
3. Use bright illumination. This will help the person distinguish detail and colors.
4. Limit the duration of "close work".
5. Provide support in a new environment until the person has become accustomed to it and can easily find his/her way around.
6. Provide support when walking (if needed).

7. Use adaptive aids such as big numbered telephones, large print books, and magnifying glasses.
8. Provide adequate handrails in stairwells and other areas where the person may need support.

HEARING

Changes:

The ear is a specialized nerve receptor for hearing and equilibrium. It receives sound waves which are converted into nerve impulses and transmitted to the brain for processing and interpretation. Hearing loss begins in early adulthood and is more common in men. It is estimated that by age 65, 30% of the population have hearing problems and that as many as fifteen percent (15%) of the population over age 75 have a total hearing loss. The loss of high frequency and low intensity sounds makes it more difficult to distinguish one word from another. Persons with Down syndrome may experience a more progressive, earlier hearing loss.

The ear also detects changes in head position. This information is interpreted by the brain and is important in maintaining balance.

Types of Impairment	Causes/Effects
Presbycusis	Changes in the inner ear, which is a fluid filled cavity, and a reduction in the number of auditory nerves which relate to a loss in the ability to hear high pitched sounds. Age related changes also produce loss in the ability to hear at low levels of intensity. Sounds such as the consonants "z", "q", "s" and "t" are difficult to hear. Combinations such as "sh" or "th" are difficult to hear. Words seem to run together and some sounds are lost altogether.
Tinnitus	A constant ringing is heard in the ear. It sounds like a distant bell or siren and is more apparent at night.
Types of Impairment	Causes/Effects
Vertigo*	Refers to a sense that the surroundings are spinning.
Dizziness*	A sense of lightheadedness and unsteadiness which may have different underlying causes.

*Vertigo and dizziness are not caused by aging but are experienced more often by the elderly and lead to increased chance of falls or fear of falling, and should be evaluated by a physician.

Detecting a Hearing Impairment:

Some signs you will be able to observe, that may indicate a hearing loss, include:

The radio or TV volume is on very loud.

They ask you to repeat things.

You notice them watching your mouth very closely.

If you turn your back to them, they do not hear or understand you.

They talk excessively loud, yet don't realize it.

They don't hear the door bell or a knocking at the door.

They don't hear the telephone ringing in another room.

If you suspect a hearing problem you may want to ask some specific questions such as:

Do you have trouble hearing?

Are there certain words you have difficulty understanding?

Do you hear a hissing or ringing noise in the background?

Does it seem like people speaking to you are mumbling?

Do you stay away from social events because you can't hear very well?

Implications:

These changes have many implications. The person may have trouble understanding speech, not only because they can't hear the sounds, but also because they have trouble distinguishing sounds. The person may feel separated from the world because he/she doesn't hear the background noises that help us stay in touch with our environment. They may act suspicious, because they think people are talking about them. This suspicious behavior may lead to a misdiagnosis of paranoia and/or behavioral and emotional problems.

The person may stop trying to communicate with other people because it is too much work or an embarrassment to him/her to ask people to repeat themselves. This behavior leads to additional withdrawal and isolation.

Suggestions:

1. Increase loudness of the voice, but don't shout, because of a process called recruitment. That is that once a person's hearing threshold is reached, the sounds get very loud.
2. Speak clearly and distinctly. As mentioned, the problem may not be volume, but the inability to distinguish between similar sounds. Speak at your normal rate, but not too rapidly.
3. Speak to the person at a distance of 3 to 6 feet.

4. Face the person you are addressing. Establish eye contact. Be sure they are attending to you.
5. Position yourself near good light so that your lip movements, facial expressions, and gestures may be seen clearly.
6. If the listener does not understand what was said, rephrase the idea in short, simple sentences.
7. Limit background noise and distraction.
8. Use alternative communication systems, such as lipreading.

Note: Hearing aids may not be the answer for all people. Some kinds of neurological losses are not helped by hearing aids. In addition, hearing aids amplify the sound, but do not make it more distinct. As a matter of fact, hearing aids may increase the problem, because they increase background noise.

TASTE, TOUCH, AND SMELL

Changes:

Changes in the senses of taste, touch and smell contribute to the individual's sense of well-being. Diminished taste perception may be attributed to: changes in the processing of taste sensations, decreased volume of saliva, decreased number of taste buds. Lifestyle habits such as smoking or tobacco use and medication side effects may contribute to diminished taste sensations.

Area of Change	Types of Change
Taste	Desensitization, especially in the ability to distinguish between taste categories such as sweet, salty, or sour is the most common change.
Touch	Sensitivity to tactile sensations, temperature, and pain become less efficient.
Smell	Decreased sensitivity to smell closely parallels that of diminished taste.

Implications:

With diminished sense of taste, it is not unusual for the older adult to increase the use of spices, especially sugar and salt in an attempt to compensate for this loss. This in turn may impact diseases, such as diabetes and high blood pressure.

Potential hazards associated with the deterioration of the sense of smell include the inability to detect gas leakage and spoiled food. Reduced sensitivity makes the elderly more

susceptible to burns, hypothermia, or hyperthermia.

PHYSICAL APPEARANCE

Changes:

There are changes in physical appearance as a person ages such as gray hair and wrinkles. However the body changes in many other ways over time.

Area of Change	Types of Change
Skin	Both the inner and outer layers of skin become thinner and lose fatty substance. Cells producing melanin, which gives skin color, are lost. Deposits of pigment occur. Wrinkles appear. Skin appears dryer and pale. Age spots are more common.
Hair	Loss of pigment cells relates to graying of hair. Thinning of hair and baldness can occur. Hormonal imbalances in women can cause growth of bristly facial hair.
Nails	Rate of nail growth decreases. The nails may thicken, appear dull, opaque, and yellow or gray in color. They often become fragile and brittle.
Musculoskeletal	Muscles decrease in bulk and skin loses fatty tissue. This causes arms and legs to look thin and bony. Loss of height can be caused by shrinkage of discs between vertebrae in the back, or by osteoporosis. Osteoporosis is prevalent among women.

Implications:

These changes, particularly if the person does not understand the aging process, may result in decreased self-concept, increased social withdrawal, and increased risk of skin injury.

Suggestions:

1. Avoid excess sun and wind.
2. Eat a balanced diet.
3. Promote healthy self-concept through education and program objectives to increase the understanding of the aging process.
4. Promote good grooming.
5. Promote good skin care. Although over-the-counter creams and lotions may be helpful, those that contain alcohol and perfume may further promote drying.

DECONDITIONING

Musculoskeletal



As a person ages, the musculoskeletal system undergoes many changes which frequently result in decreased strength (as much as 50% by age 80). The changes include but are not limited to, decreased bone mass, decreased joint lubrication, decreased muscle mass, decreased muscle flexibility, and joint stiffness. These changes are aggravated by metabolic changes such as decrease in the potassium available to the body.

The decrease in potassium results in a decrease in energy which in turn results in a decrease in exercise. The decreased exercise causes additional deterioration of the musculoskeletal system.

Age Related Change	Types of Change
Bones	After age 40, there is a progressive bone loss which may lead to increased susceptibility to breaks or fractures. At menopause, women experience an accelerated loss due to lack of estrogen.
Muscles	Muscle mass and strength decrease with age by as much as 50%. There is a decrease in the body's potassium as well. It becomes more difficult to do physical labor. As a result of these changes, a cycle is created. Lack of exercise leads to muscle loss and inability to do exercise. Decrease in potassium produces a lower energy level and less desire to exercise.
Posture	Changes such as rounded shoulders and an increased curve in the upper back, occur frequently in the elderly. These changes may be caused by decreased muscular strength and loss of joint flexibility.

Age related disorders of the musculoskeletal system can incapacitate elderly persons. By age 65, virtually all persons will show some form of joint disease. A lubricant fluid which helps prevent bones from rubbing together decreases. Persons with some developmental disabilities may have experienced difficulties at an early age (e.g., cerebral palsy). These can worsen with old age.

Age Related Disorders	Cause/Effects
Osteoarthritis	Most severe on hips, lower spine & knees. Pads of cartilage covering the ends of the bone harden and splinter. Decrease in lubricating fluids causes bones to rub against one another. Outgrowths of bones may appear at joints. More women than men suffer from this. Overweight persons are also more prone to suffer.
Osteoporosis	Bones are lacking mineral content. They become thin and break more easily. When fractures and immobility occur, complications can result. Blood clots can form which cause heart attacks.
Age Related Disorders	Cause/Effects
Rheumatoid Arthritis	Begins at an earlier age and affects more women than men. Involves inflammation of connective and supportive tissue and commonly affects hands and feet. There may be some deformation as disease progresses. May be periods without pain and periods of intense pain. Stress can exacerbate the symptoms.
Gout	Caused by body's inability to excrete uric acids. Deposits of acid form in large crystals on kidneys or cartilage. This can cause inflammation of joints which limits mobility and causes pain.

Implications:

The implications of musculoskeletal changes are discomfort, lack of mobility, and decreased activity. The older person may also experience fear of falling and difficulty with steps. These fears may lead to depression because the person sees himself/herself in failing health and unable to function independently.

Suggestions:

1. Apply heat to affected joints. In some cases, alternating with cold. (Obtain physician recommendation).
2. Maintenance of appropriate weight.
3. Well planned exercise program using low stress impact (e.g., walking, swimming). Avoid the vicious circle of decreased energy yields decreased exercise yields decreased energy yields further deterioration (loss of bone mass, flexibility and strength).
4. Adaptive aids (velcro on clothing, and other aids to increase independent functioning).
5. Pain treatment and control.
6. Physical therapy.

RESPIRATORY

Changes:

There are numerous changes in the respiratory system as a person ages. The lungs become less efficient because the lower parts collapse and the size of the airways decreases. There is less movement of secretions in the system because of decreased ciliary (little hair like fibers lining the lungs and airways) action.

Implications:

The person is at increased risk for pneumonia and lungs are less efficient in oxygenating blood.

Suggestions:

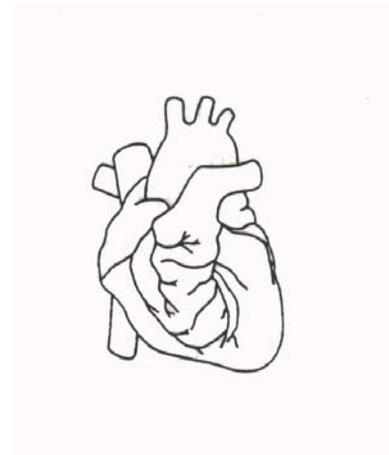
1. Increase exercise.
2. Decrease or eliminate smoking.
3. Get flu shots, etc.

CARDIOVASCULAR

Changes:

Many of the changes normally associated with cardiovascular aging are actually due to disease or deconditioning. Although the cardiovascular system undergoes changes with age, which render it less efficient and more prone to dysfunction, these changes generally do not affect the ability to perform everyday activities. The disease free cardiovascular system will function well throughout life.

Typical age related changes in the heart include an increase in the amount of fat deposits on the surface of the heart, thickening of the lining of the heart, reduction in the amount and size of cardiac muscle cells, and reduction in the amount of oxygen that can be delivered to the rest of the body. These changes may cause a decrease in cardiac output, increased response to exercise, increase in the amount of time the heart rate takes to return to normal after exercise, increase in the general heart rate, and a decrease in circulatory efficiency.



Types of Change	Causes/Effects
Hypertension	Diagnosis is based on blood pressure readings above 150/90 with 120/80 as normal. Called the "silent killer," it is often undetected until it has affected and weakened the system as a whole. The heart also enlarges and this hastens the frequency of such conditions as heart disease, strokes and kidney failure.
Heart Disease	Caused by flow of blood to and from the heart being blocked by: a) hardening of blood vessels; b) build up of fatty residue in the veins and arteries. It can also be caused by a weakening in the heart muscle. When the heart muscle cannot pump the needed amount of blood, symptoms occur. A blood clot may form in the narrowed artery.

Implications:

The results of cardiovascular changes include but are not limited to: edema (swelling), strokes, angina pectoris (chest pain), and myocardial infarction (heart attack). These changes may result in fear of exercise, easy tiring, and sensitivity to cold.

Suggestions:

1. Decrease or eliminate smoking.
2. Lose weight, if obese.
3. Decrease sodium, alcohol, fat, cholesterol, and caffeine intakes.
4. Get adequate rest.
5. Exercise regularly.

GASTROINTESTINAL

Changes:

Aging effects most parts of the gastrointestinal (digestive) system. The most obvious change is the loss of teeth. It is estimated that less than seventy-five percent (75%) of the older population has adequate dentures. The senses also change. As the ability to smell decreases, there is a related decrease in the ability to taste food. As a result of decreased saliva production and wave in the esophagus action, it is more difficult to swallow.

Areas of Change	Types of Change
Dentition	Lack of healthy teeth or properly fitting dentures affects nutrition and diet. It's especially difficult to eat fresh fruit and vegetables without good dentition.
Sense of Taste	The threshold of taste and smell increases with age. More stimulation is needed, for example, for something salty to taste salty. Due to this, food does not taste as good as it once did and appetite can decrease.
Esophagus	A common complaint is difficulty swallowing. It may be caused by thickening of the lining of the esophagus or by decrease in amount of saliva. Diseases more common to older persons are cancer of the esophagus and hiatal hernia. The hernia can cause heartburn, chest pains and belching. Risk factors in cancer of the esophagus include smoking or drinking, being over 55 years of age, black, a male, or a city dweller.
Esophagus	A decrease in the secretion of gastric juices produces certain problems. These include indigestion and peptic or duodenal ulcers. Indigestion produces heart burn and pain in the stomach. Ulcers can be thought of as open sores on the stomach. Pain may be alleviated by eating or by medications prescribed by the physician.
Areas of Change	Types of Change
Intestinal Tract	Constipation can be produced by loss of abdominal muscle tone and/or taking medications such as antacids, diuretics or sedatives. Constipation can be complicated by being confined to bed or immobility. Diverticulosis, an intestinal disease, is aggravated by constipation.
Hemorrhoids	Hemorrhoids are blood vessels which become swollen by straining when constipated, lifting heavy objects, chronic coughing, being overweight or by pressure from a rectal tumor. Two signs are pain and rectal bleeding. Rectal bleeding is also a sign of cancer, therefore physician should be consulted when this condition occurs.

Implications:

The effectiveness of dentures is estimated to be only 12% of ones own teeth. Consequently, the denture wearer must chew food much longer in order to reach the same level of mastication. Chewing difficulties may lead to dietary modifications that include softer foods, reducing dietary bulk and potentially creating digestive problems such as constipation. The changes in the gastrointestinal system may effect not only the person's ability to eat some food but also their appetite. Changes in eating habits can also lead to problems with poor nutrition.

Suggestions:

1. Provide soft, easy to chew foods.
2. Ensure good dental hygiene.
3. Serve small frequent attractive meals.
4. Serve the large meal early in the day.
5. Use a relaxed atmosphere.
6. Increase liquids, fruits, vegetables, and grains.
7. Increase exercise.
8. Avoid foods with seeds (e.g. tomatoes).
9. Refrain from regular use of enemas or laxatives.
10. Consider texture and consistency of foods as needed.

Texture. As indicated above, individuals who have difficulty eating may require modification of the texture or consistency of their food. The changes are usually fairly easy to obtain. For our purposes, texture is the resistance of food to being broken into smaller bits. Highly textured foods are more difficult to chew; foods without texture are smooth, soft, and can be eaten with little or no chewing. For example, beef prepared in decreasing amounts of texture would be:

1. Beef steak -- highly textured, difficult to chew.
2. Minute steak -- thinner, tenderized, somewhat easier to chew, still having a lot of texture.
3. Broiled or fried hamburger -- the meat has been chopped, but it is still solid, so chewing is required.
4. Chopped meat in spaghetti sauce -- no longer solid, requires very little chewing.
5. Pureed or strained (baby food) beef -- requires no chewing.

Mixed foods such as soup and stew may contain foods of varying texture. Adding ingredients such as raisins to pudding may make it too difficult for some people to chew. Some textured foods such as crackers and potato chips offer little resistance and become soggy in the mouth. As a result, these can be managed adequately by some people who have difficulty with other highly textured foods.

Consistency. How "runny" a food is determines consistency. Consistency is characteristic of semisolid foods. Adding more and more milk to mashed potatoes decreases the consistency. People who have some difficulty manipulating food in the mouth may have difficulty eating foods with very thick consistencies, i.e., mashed potatoes or peanut butter. Thinning a thick food by adding water will make the food easier to eat. However, thin consistencies cause problems for some people because they are difficult to swallow. As a result, we may want to thicken their beverages so they can swallow them.

GENITOURINARY SYSTEM

Changes:

The capacity of both the kidney and bladder diminish with age. Both men and women have more urinary tract problems in middle and old age. For women, incontinence is more common. For men, prostate diseases are more common (e.g., acute prostatitis; benign prostatic hypertrophy and prostate cancer).

Older adults do not lose their interest in or capacity for sexual activity because of age-related changes. Any decrease in sexual functioning is related to social circumstances, illness, adverse medication effects, or myths and attitudes. The most common reason for decreased sexual activity in the older adult is the lack of a partner.



Hormonal changes due to aging result in physical changes for both men and women. Menopause usually begins around 50 years of age. Many other changes can occur in the body as a result of decreased estrogen (e.g., osteoporosis, increased heart attacks).

Type of change	Cause/Effect
Kidney	There is a slowing of the filtering process by the kidneys, increasing the potential of drug overdose since the amount of medicine in the bloodstream will tend to concentrate more quickly.
Type of change	Cause/Effect
Bladder	A reduced bladder capacity will increase the frequency of urination. Weakening of muscle tone may also create difficulty in the emptying of the bladder, making the older adult more susceptible to urinary tract infections.

Incontinence	Urinary incontinence affects 1 in 10 adults, of which only 15% will be male. Incontinence is not caused directly by aging. Life changes such as childbirth, diseases that restrict mobility or affect cognitive skills, changes in muscle tone and bladder capacity, and medication side-effects are the primary causes.
Prostrate Disorders	Enlarged prostrate may begin to impede urination and prevent the bladder from emptying causing infections and possible kidney damage. Symptoms include increased urgency to urinate, dribbling after urination and sometimes difficulty in urinating.
Hormonal Changes	Women will notice it takes longer for vaginal lubrication and the vaginal walls are generally more easily irritated. Generally, the orgasmic phase becomes shorter and less intense for both males and females.

Implications:

Individuals experiencing incontinence may restrict activities to avoid accidents and may develop lowered self esteem, withdrawal, isolation, and even depression. It is imperative that anyone with incontinence be examined by a physician. Incontinence is a sign that “something isn’t right” and one third of the cases can be successfully prevented. In those cases where total prevention is not possible, frequency and degree of leakage can be improved.

The first step in treating sexual dysfunction is a complete physical that includes the evaluation of all medications being taken. Many causes of sexual dysfunction are reversible. For today’s older adult, perhaps the greatest challenge in maintaining sexual activity is overcoming societal attitudes. Myths which view the elderly as sexually nonfunctional and uninterested may become a self-fulfilling prophesy.

CENTRAL NERVOUS SYSTEM

Changes:

In the absence of disease, nervous system functioning remains intact throughout life. The most dramatic age related change is a decrease in the number of neurons resulting in a 10-12% decrease in brain weight. Excessive alcohol use, smoking, or a polluted environment can accelerate loss. There is a slight decrease in nerve conduction velocity which slows both reflex and voluntary responses. It may take slightly longer to retrieve information from memory store or learn new skills because of the reduction of transmission and processing within the nervous system.

Areas of Change	Types of Change
Reaction time/psychomotor performance	The speed with which older adults perform tasks may decline from 20% to 50%. The speed with which the central nervous system processes information also decreases with age. Possible explanations of this slowing down include: neural deterioration, declining health, changes in the senses, slower information processing, or decreasing blood flow to the brain. Research indicates that practice and exercise can improve reaction time.
Memory	Severe memory loss is not a part of normal aging. While some problems in short term memory occur it is usually associated with poor encoding strategies or in organizing and processing information. The elderly have difficulty in acquiring or retaining information which is not meaningful to them. Problems with memory can be reduced by using organizational strategies and allowing more time for recall of information.
Learning/Intelligence	<u>Research indicates that age alone does not affect the ability to learn and intellectual decline is minimal.</u>

These changes can be aggravated substantially by diseases more prominent in old age.

Age Related Disorders	Cause/Effects
Cerebrovascular Accident (CVA, stroke)	Occurs when a portion of the brain is deprived of oxygen. Strokes can be caused by a blockage or bursting of an artery in the brain. A stroke does not worsen over time. There is, however, permanent brain damage. The effects of a stroke depend upon the amount and location of the damage. Transient ischemic attacks (TIAs) produce the symptoms of a stroke, but complete recovery occurs within 24 hours.
Parkinson's Disease	A slowly progressive disorder resulting from a loss of neurons in the brain stem and a lack of the neurotransmitter dopamine. It is characterized by a resting tremor, stiffness, and slowness of movement. Common complications include falls due to lack of mobility, reactive depression, constipation and hiccups.
Dementia	A progressive loss of brain functioning characterized by memory impairment, loss of concentration, loss of intellectual functioning, and disorientation.
Alzheimer's Disease	With Alzheimer's disease intellectual deterioration and emotional and behavioral abnormalities occur. Atrophy, plaques, and neurofibrillary tangles are found in the brain. Incidence increases with age and half of all dementias fall within this category.
Multi-infarct dementia	A series of small strokes cause small area of the brain to be destroyed. These strokes are the indirect result of a hardening or narrowing of the arteries supplying blood to the brain (cerebral arteriosclerosis). Multi-infarct dementia comprises 15-20% of all dementias.

Implications:

The implications of the changes in the brain are not clear. However, it is clear that people continue to learn and to obtain new skills throughout their lives. An older person's experiences and increased vocabulary more than compensate for any difficulties learning new tasks. How aging effects memory is also unclear. Long-term memory may remain intact. However, the implications for short-term memory are not as well documented.

Suggestions:

1. Simplify learning tasks.
2. Allow the older person plenty of time to process and answer questions.
3. Eliminate distractions.
4. Teach how to organize.
5. Have them use memory aids (e.g. daily pill boxes).
6. Separate out complaints from real concerns. Some forgetfulness is normal for all of us.
7. Provide peer support. Try to make life meaningful. Promote social interactions.
8. Provide stimulating environments and challenges to keep physically and mentally sharp. The old adage "If you don't use it, you lose it" holds true for older people.

SLEEP

As people age they may find they need less sleep. However, if they don't get enough sleep, they will have fatigue, irritability, and decreased concentration.

Types of Change in Sleep	Causes/Effects
Change in sleep habits	Time spent sleeping decreases. Older persons may wake up more often at night. It may be harder to get to sleep. They may wake up earlier.
Insomnia	Insomnia is common, resulting in fatigue, irritability and poor concentration. Some older persons take hypnotic drugs for insomnia. Drugs should not be taken on a daily basis due to the possibility of dependency, interaction with other medication, anxiety and nightmares upon cessation of drugs.

Implications:

Major causes of sleep disturbances are sleep apnea (brief periods when breathing stops), periodic leg movements, heartburn, cardiovascular disease, dementias, drugs, anxiety, and depression.

Sleep promoting drugs should be avoided because people develop a dependency or a tolerance to the drug, and people taking other medications risk the possibility of drug interactions. In addition, sleep medications may decrease rapid eye movement sleep and produce anxiety and nightmares. Lastly, because many elderly persons metabolize drugs more slowly than younger people, the drugs may decrease alertness the next day.

Suggestions:

1. Encourage the person to limit naps.
2. Promote regular habits. People should get up and go to bed at a similar time each day.
3. Increase exercise, but not too vigorous or too close to bedtime.
4. Use white noises (constant background noises i.e. fan) to mask distractions in the environment.
5. Check room temperature. Be sure it is cool.
6. Provide a light snack before bedtime. Foods such as warm milk have a natural sleep enhancing chemical.
7. Decrease caffeine and alcohol. Alcohol may initially enhance sleep, but it has a rebound effect, as a result one awakes and is not able to get back to sleep.



OTHER HEALTH ISSUES

Mouth Care:

Mouth care includes daily brushing, frequent flossing, and fluoride treatments. Even the toothless person needs mouth care, because a white curd-like fungus, Monilia, can build up in the mouth, and increased bacteria in the mouth can lead to aspiration pneumonia. Oral care needs to be provided on a daily basis, because unremoved plaque can turn to calculus in less than twenty-four (24) hours.

Skin Care:

Good skin care is important for the elderly. Use a cleansing soap that does not dry the skin.

In addition, creams that add lubrication should be applied to the skin frequently.

Foot Care:

Foot care is an important issue for the elderly. They need to keep their toe nails trimmed, feet clean and dry, and wear properly fitting shoes.

Alcoholism:

In the elderly increased frequency of illness and disease, losses, and isolation are factors that may lead to alcohol abuse. Tolerance for alcohol is less with age and there are often additional problems when medication and alcohol are combined. Estimates indicate that between 2 and 10 percent of the older population are alcoholics.

Medication:

As the body ages, the ability to absorb and excrete drugs is altered. Older people tend to self-medicate with over-the-counter drugs and prescriptions. They may take multiple medications which may interact with each other and produce adverse side effects (e.g, dementia, depression, delirium). The use of medications should be closely monitored.

Confusion:

Confusion may be the result of infection, heart or liver disease, malnutrition, drug reactions, dehydration, surgery or anesthesia, isolation, depression, or sudden environmental changes rather than brain dysfunction.

FEEDBACK EXERCISE III

1. What are some of the implications of hearing problems for the older person?
2. How can staff members/professionals alleviate some of these hearing problems?
3. What are some changes that occur as a result of aging on the musculoskeletal system?

What are some of the implications of the musculoskeletal deconditioning?

What can staff do to assist the person to continue to maintain independence while experiencing these changes?

4. What are some of the changes in the respiratory system as a person ages?
5. What are some of the suggestions to alleviate cardiovascular problems?
6. What are some of the changes in the gastrointestinal (digestive) system as a result of aging?

How can we assist individuals experiencing these changes?

7. Match the following causes/effects with the types of impairment in vision listed below.

_____ Words closer than 12" become difficult to read.

_____ Colors such as blue and violet, at the lower end of the color spectrum, are difficult to see because the eye's lens begin to yellow.

_____ Occurs when lens become opaque or clouded. When light hits the eye it produces a glare and reduced vision.

_____ Occurs in situations of low light. Higher degrees of illumination are needed.

_____ Can be due to tear gland producing too few or too many tears. Both situations are correctable.

A. Cataracts

B. Irritation

C. Presbyopia/Farsightedness

D. Change in color perception

E. Decrease of sharpness of vision

8. Listed below are different kinds of beef. Put them in sequential order moving from highly textured beef to lower textured beef. Use numbers 1 - 5, one being the highest degree of textured and five the lowest degree of textured.

A. _____ Broiled or fried hamburger

B. _____ Pureed or strained beef

C. _____ Beef steak

D. _____ Chopped meat in spaghetti sauce

E. _____ Minute steak

9. How can staff members/professionals help individuals compensate for some of these vision problems?

10. What risks are associated with deterioration of the sense of smell and the sense of touch?

11. What can staff do to assist individuals experiencing age related changes in their physical appearance?

12. What changes occur in the genitourinary system as a result of aging and what are the implications of these changes?

13. Use the information in the module to argue for or against the statement: "I can't learn this because I'm too old!"

14. Why are individuals discouraged from using sleep promoting drugs?

15. What suggestions would you give an older person who is having difficulty sleeping?

UNIT IV: DEVELOPMENTAL DISABILITIES AND ALZHEIMER'S DISEASE

OBJECTIVES: After completing this unit, staff members will be able to:

- Describe the symptoms and general course of Alzheimer's disease in the general population
- Explain why it is critical that a person showing signs of dementia have a complete medical workup
- Identify the risk factors for Alzheimer's disease for adults with developmental disabilities
- List behavioral symptoms of Alzheimer's dementia in adults with intellectual disabilities
- State guidelines for care providers to assist with changes in behavior associated with Alzheimer's disease

WHAT IS ALZHEIMER'S DISEASE?

Alzheimer's disease is a slowly progressive, degenerative disorder of the brain that eventually results in abnormal brain function and death. The disease was first described in 1907 by a German physician, Dr. Alois Alzheimer.

Alzheimer's disease is a disorder marked by a gradual decline in brain function. It used to be assumed that this change was a normal part of aging that we called "senility". Some persons develop this condition when they are as young as 40 years of age. However, the disease is most common in persons over the age of 65. It is estimated that approximately 10 % of persons over 65 may have Alzheimer's disease and that up to 50 % over 85 may be affected.

Alzheimer's disease is not a normal part of the aging process. It is not "hardening of the arteries". It is not contagious, and it is not known how it can be prevented. The physical changes in the brain are very similar among those affected. However, the behavioral and psychological symptoms that result are complex and may differ from person to person. These symptoms lead to a form of "dementia" which is the loss of mental skills and abilities, including self-care capabilities. As Alzheimer's disease progresses, these losses will result in total dependency for even the simplest activities.

SYMPTOMS OF ALZHEIMER'S DISEASE

The early symptoms of Alzheimer's disease in the general population often include:

- **Language problems.** The person cannot find the right word or name for a familiar person, place or object. This is not the same as taking longer to recall a word. It is

far more than the "occasional" slip of a name that everyone experiences.

- **Loss of recent memory.** The person may forget that he or she just had breakfast or has left something cooking on the stove, or may check and recheck that the bed has been made. However, recall of events from the distant past is often unaffected.
- **Loss of a sense of time and place.** The person may become more and more confused about what day it is, or forget the route to well-known places.
- **Decline in activities of daily living.** The person may exhibit an unexplained loss of activities of daily living (ADL) skills. What once was easy for a person may now be difficult.
- **Personality changes.** These may be so slight that, at first, they are difficult to notice. Some people become more quiet and withdrawn. In other cases, they may become more and more restless. Some persons may start to get angry over little things or have sudden changes of mood for no apparent reason.

THE GENERAL COURSE OF ALZHEIMER'S DISEASE

First (or onset stage):

The initial symptoms often appear very gradually. There may be some minimum memory losses, particularly of recent events. The individual may experience difficulty in finding the right words to use during casual conversations. Work performance may begin to deteriorate and changes in behavior may start to become obvious. These changes may last for a period of up to five years.

Second (or progressive stage):



The symptoms noted during the onset stage now become more obvious. The most obvious sign of movement to this stage is distinct problems with language. Persons affected may have difficulty naming objects or with maintaining a logical conversation. They may also have difficulty understanding directions or instructions. They often become easily disoriented with regard to what day it is (time), where they are (place), and who they are with (person). Confusion and the resulting frustration are often evident. Memory losses become even more pronounced. They may also begin to experience loss of self-care skills, including the ability to use the toilet (incontinence). Severe changes in personality may begin to become obvious, and their social behavior may be marked by suspiciousness (paranoia) and delusions. These changes may last for up to about twelve years.

Third (or terminal stage):

Persons affected now experience substantial dysfunction. Basic skills such as eating or drinking are forgotten. Because of eating problems, many persons may experience a substantial loss of body weight (up to 20-30 percent). They may eventually lose their ability to maintain balance and walk. Their ability to recognize other persons and their environment is gone. Both long- and short-term memories are lost. At this stage, persons affected require complete 24-hour care and often become bedridden and inactive. Because of this, they are at increased risk for any infection, especially pneumonia, and consequently are far more likely to die. These changes, leading to death, may last for three or more years.

OTHER CONDITIONS WHICH PRODUCE THE SAME SYMPTOMS

There are numerous other disorders or conditions that result in symptoms similar to those of Alzheimer's disease. Many of these conditions are treatable. It is therefore crucial to determine the cause of the symptoms and not assume they are due to Alzheimer's disease.

If a diagnosis of Alzheimer's disease is assumed without adequate evaluation, the adult with a treatable condition may be deprived of remedies that could help return him or her to normal function. A variety of psychosocial and medical procedures must be used to rule out associated disorders as the cause of personality or behavior changes that otherwise could be mistakenly attributed to Alzheimer's disease.

It must not be assumed that someone has Alzheimer's disease because he or she exhibits some symptoms of the disease. Other common causes of these symptoms include: stroke, depression, medication reactions, thyroid disease, nutritional deficiencies, brain tumors, head trauma, subdural hematoma, and normal pressure hydrocephalus.

Although Alzheimer's disease is the most common cause of dementia, it is only one of the many causes. There are also "related disorders" that caused various forms of dementia. These include multi-infarct dementia and conditions like Huntington's disease, Parkinson's disease, and Creutzfeldt-Jakob disease.

There are also "associated disorders," such as thyroid abnormalities, arthritis, hearing loss, temperature sensitivity and sleep pattern changes, that may occur at the same time as Alzheimer's disease but which are not cause by Alzheimer's disease. These conditions may be reversible or treatable. They result in dementia-like symptoms but do not actually cause the permanent brain changes that result in dementia.

RISK FACTORS FOR ALZHEIMER'S DISEASE OR DEMENTIA AMONG PEOPLE WITH DEVELOPMENTAL DISABILITIES

Most adults with developmental disabilities are at the same risk for Alzheimer's disease (or other forms of dementia) as are individuals in the general population. However, there are individuals with a developmental disability who are at greater risk of developing the disease when the following are present:

- If the individual is over 40 years of age and has Down syndrome.
- If the individual has had some form of head injury, especially severe or multiple injuries.
- If the individual has a history of Alzheimer's disease in his or her family.

The presence of these factors does not necessarily mean that Alzheimer's disease (or some other form of dementia) will occur. However, the presence of one or more of these risks should alert the care provider to the increased probability of the person with the developmental disability developing this disease. When there is suspicion about the presence of Alzheimer's disease, medical follow-up must be done to ensure a proper differential diagnosis.

Studies at the New York State Institute for Basic Research in Developmental Disabilities have shown that the rate of occurrence of Alzheimer's disease among persons with a developmental disability appears to be about 2 to 3 percent of adults age 40 and older. People with Down syndrome make up about 60 percent of the adults with intellectual disabilities who show signs of probable Alzheimer's disease.

DOWN SYNDROME, AGING AND ALZHEIMER'S DISEASE

People with Down syndrome may experience health problems as they age that are different from those experienced by older persons in the general population. The presence of extra genetic material found among persons with Down syndrome may lead to abnormalities in the immune system and a higher susceptibility to leukemia, seizures, cataracts, respiratory illness, and heart conditions. Persons with Down syndrome also experience premature aging - that is, they show physical changes related to aging some 20 to 30 years ahead of persons of the same age in the general population.

With increased age, persons with Down syndrome may experience "typical" hearing loss and vision changes that are "expected to accompany being older," but will do so 20 to 30 years before other persons in the general population. Vision problems may be mostly due to cataracts. There may also be problems with motor abilities and changes in the skin, nerve, muscle, digestive, and urinary systems. Compared to age peers, people with Down syndrome have higher rates of Alzheimer's disease. Adults with Down syndrome are often in their mid to late 40s or early 50s when symptoms of Alzheimer's may first appear, while symptoms first appear in persons in the general population beginning in the late 60s.

Although about 20 to 40 percent of adults with Down syndrome show the behavioral symptoms of dementia, upon autopsy nearly all older adults with Down syndrome show the brain changes associated with Alzheimer's dementia. The progression of the disease takes, on the average, about eight years - somewhat less time than among persons in the general population. Men and women seem to be equally susceptible.

The symptoms may be expressed differently among adults with Down syndrome. For example, at the early stage of the disease, memory loss is not always noted, and all symptoms ordinarily associated with Alzheimer's disease may not occur. Generally, changes in activities of daily living occur, and there may be the onset of seizures when there had been no seizures in the past. Cognitive changes may also be present, but they are often not readily apparent or they may be ignored because of the individual's limited general functional level.

SIGNS THAT AN OLDER PERSON WITH INTELLECTUAL DISABILITIES MAY BE DEVELOPING ALZHEIMER'S DISEASE

Recent studies of individuals with intellectual disabilities have shown behavioral symptoms of Alzheimer's dementia in such adults may include, but are not limited to: (1) the development of seizure in previously unaffected individual, (2) changes in personality, (3) long periods of inactivity or apathy, (4) hyper-reflexivity, (5) loss of activity of daily living skills, (6) visual retention deficits, (7) loss of speech, (8) disorientation, (9) increase in stereotyped behavior, and (10) abnormal neurological signs (Janicki, Heller, Seltzer & Hogg, 1995).

DIAGNOSING ALZHEIMER'S DISEASE

There is no single diagnostic test for Alzheimer's disease. If Alzheimer's disease is suspected, a complete physical examination and frequent medical, neurological, and psychological evaluations are strongly recommended to establish the progressive nature of the symptoms. This is particularly true for adults with a developmental disability.

A "definitive" diagnosis can only be made at the time of autopsy. The numerous tests and evaluation procedures will result in a "possible" or "probable" diagnosis of Alzheimer's disease. To make a probable diagnosis of Alzheimer's disease, it is necessary to observe a well-documented progression of symptoms and rule out any other possible conditions or disorders. To help secure such a probable diagnosis, complete evaluations must be performed periodically. Such evaluations or tests are necessary to rule out conditions that are not Alzheimer's disease, or are reversible forms of dementia.

A complete evaluation should include:

- A detailed medical history, provided by a family member, caregiver or someone else well acquainted with the individual. This is the best way to determine accurately whether or not there has been progressive deterioration and personality changes, problems with memory, and difficulty with daily activities. As much as possible, the person should be involved in this process and asked

what he or she feels is changing.

- A thorough physical and neurologic examination, including the testing of sensory-motor systems, to rule out other disorders.
- A “mental status test” to evaluate orientation, attention, recent recall and the ability to calculate, read, write, name, copy, draw, repeat, understand and make judgments. Mental status evaluation may not be useful with individuals with preexisting cognitive limitations, such as severe intellectual disabilities. Because of this, mental status examinations need to take into account the individual’s past history and abilities and should never be the sole clinical assessment.
- A psychiatric assessment to rule out the presence of psychiatric disorder, particularly depression.
- Neuropsychological testing to measure a variety of functions that include memory, orientation, language skills, intellectual abilities, and perception.
- Routine laboratory tests, including blood work, health exams, such as urinalysis, chest x-ray, electroencephalography (EEG), and electrocardiography (EKG), as well as certain specialized tests as deemed appropriate. Imaging techniques, such as CT (computerized axial tomography) and MRI (magnetic resonance imaging), can be useful in showing progressive brain atrophy and helping to rule out other selected dementias. However, these techniques are costly and are mostly used in research.

Although the above assessments apply to most people with a developmental disability who may be suspected of having Alzheimer’s disease, the sole use of mental status and psychiatric assessment is inappropriate, especially for persons with severe intellectual disabilities. It is recommended that, at minimum, annual or more frequent evaluation and measures be used to look for changes in existing skills.

BEYOND THE DIAGNOSIS

Once the suspicion of Alzheimer’s disease has been clinically confirmed, the person’s family, caregiver, or paid providers may need to assist the person to make changes in their daily routine. First and foremost, the person must feel safe and secure in his or her environment. As a result of the complications associated with Alzheimer’s disease, what may have been comfortable and familiar for the individual will become unrecognizable and result in unpredictable behavior. For example, some persons may have changes in behavior that make them seem suspicious and delusional. To help with the changes in behavior, consider the following:

- Emphasize maintaining abilities, particularly those affecting dignity (eg., toileting, eating), rather than trying to teach new skills.
- Keep changes in environment and daily routine to an absolute minimum.

- Simplify routines and reduce choices to minimize feelings of anxiety and frustration.
- Use patience and redirection.
- Keep verbal requests simple and provide general supportive care.
- Maintain self awareness by using reminiscing and talking about past experiences when appropriate.
- Help the person maintain his or her orientation by naming events for the day, reminding him or her of the day, time and place and repeating the names of others around him or her.
- Try not to force him or her back to your reality, but also don't allow a move into a delusion that you may be inadvertently reinforcing.
- Reassure the person daily, even when there is no response.
- Try to understand the words and symbols the person is using in communicating.
- Be patient, and don't try to force the person to understand your means of communicating; adapt to his or hers.
- Provide appropriate foods and liquids to maintain nutrition and hydration.
- Respond to suspicions and delusions with reassurance.
- Consult a physician about stopping nonessential medications, and when appropriate, assume responsibility for giving the person his or her needed medications.
- Minimize toileting accidents by establishing a toileting routine.
- Convey affection and protection by a quiet voice.
- Use touch for reassurance and praise.

To help with changes in program practices, consider the following:

- Provide a familiar and safe environment.
- Provide closer supervision to minimize confusion and disorientation.
- Maintain present level of independence by increasing staff supervision, prompts and hands-on care.

- Modify the individual's program or support plan to anticipate changing activities of daily living (ADLs) and supervision needs.
- Monitor and document increased episodes of confusion, disorientation, or memory lapses to become more prepared as they occur in the future.
- Continue assessments for mobility, safety and ADL needs.
- Inform staff, family members, and caregivers of changes in the plan of care.
- Seek to identify “triggers” that result in inappropriate or dangerous behavior and try to minimize their occurrence.

OTHER CONCERNS

Other concerns include how to help staff adapt programs and services to changes that result from Alzheimer's disease, how to provide service with dignity and respect, how to help adults with possible Alzheimer's disease “age in place”, and how to prevent or defer changes in residence.

In some programs, particularly those governed by state regulations requiring active treatment, staff may need to emphasize a different approach to care. The program plan should be adapted to reflect the behavioral and physical changes the person may experience during the various stages of the disease. Program philosophies that emphasize choice-making may need to be reevaluated, because making choices can be very confusing and frustrating for someone with Alzheimer's disease.

As the disease progresses, staff need to be prepared to adapt treatment practices to the changing needs of the individual. These adaptations should reflect a knowledge of the course of Alzheimer's disease and the potential for diminishing abilities among self-care, communication, and orientation skills. A balance should be maintained between compensating for loss of skills and maintaining development.

Early signs and symptoms of Alzheimer's disease do not necessarily warrant changes of a program or residence. The adult should be allowed to “age in place” with dignity and respect. Many adaptations can be made to the person's program or home environment to make it safe and practical. Modifications in activities and supervision may be necessary.

Many caregivers will continue to provide care despite the difficulties. However, with the advanced progression of the disease, particularly when there is total loss of self-care skills and mental abilities, some caregivers or service providers may be faced with the difficult decision of whether or not to transfer the individual to a facility that can provide appropriate long-term care.

The need to change residence can be reduced by providing increased supports to the

individual. Providing such supports should always be considered prior to a change in the person's residence. Those at jeopardy of having to change residence as the disease progresses include persons who are living:

- With a caregiver who may be unable to continue supervision and supports on his or her own, unless he or she receives additional assistance.
- Alone or with a spouse or friend and who may be at risk for personal injury due to memory loss, disorientation, and personal skills deterioration.
- In a residence where the person's needs have substantially changed due to an increased need for supervision and nursing care, the individual's behavior has a marked negative effect upon others in the residence, or the individual's overall deteriorating condition transcends the level of care which can be provided in the residence.

HELP FOR FAMILIES AND CAREGIVERS OF A PERSON WITH A DEVELOPMENTAL DISABILITY AND ALZHEIMER'S DISEASE

When an individual with a developmental disability has been living with family members, family members may need to plan for future care in a residential setting that is equipped to provide for a person with a developmental disability who has Alzheimer's disease. However, until that time, many things can be done to provide in-home supports.

Many family members and caregivers of an adult with a developmental disability have provided a lifetime of affection, support, and care while watching the individual progress and become more independent. It is particularly difficult for a family member or caregiver to watch his or her relative lose skills associated with the onset of Alzheimer's disease. Therefore, it is very important to obtain services and supports during this difficult time.



Certain specific services may be helpful in supporting the care that families are providing:

- Home care services - These include having a homemaker assist in the home or having a nursing aide provide personal care to the individual with Alzheimer's. It may also include home-delivered meals, friendly visiting, and the services of a senior companion. For the names of agencies that provide home care services in your community, call your local area agency on aging or look in the yellow pages of your telephone directory (generally under "Home Health Services").
- Adult day care - Available in many communities, this program may offer a brief respite from caregiving and an opportunity for the person with Alzheimer to become involved in different day activities.

- Overnight or weekend respite - Either in the home or at another setting, respite offers a chance for the caregiver to take a vacation or other short break from caregiving.
- Hospice - This includes special support services in the home or within a specialized hospice setting during the last six months of life. Hospice services are for persons who are terminally ill as well as for their caregivers.
- Financial or legal aid - This includes aid in arranging for payment of care and help in settling legal concerns, such as wills and trusts. For information on how to obtain such aid, consult your local area agency on aging, local chapter of the Arc, or other local disability agency.
- Local support groups - These include counseling or other group supports with persons in a similar situation. For information on how to obtain such aid, consult your local Alzheimer's Association or local area agency on aging.

Some area agencies on aging or local senior services agencies maintain special caregiver assistance programs. Some of these include special supports for parents with a son or daughter with a developmental disability. These programs can help families obtain specialized in-home services and other supports. To receive more information regarding any of these services, call your local agency on aging or local chapter of the Arc.

If you are providing care to an individual with Alzheimer's disease, you may want to participate in a support or educational group. These groups are for people in similar caregiving situations who meet regularly to share experiences and advice with each other and learn about resources available to them.

SUMMARY

- Alzheimer's disease is a slowly progressive disorder that eventually leads to death. It is not a part of normal aging.
- Symptoms of Alzheimer's disease include losses in language, recent memory, orientation, activities of daily living, and changes in personality.
- Many conditions that are treatable produce symptoms that are similar to Alzheimer's disease. It is important for adults showing signs of dementia (loss of mental disabilities) to have a complete medical workup.
- Persons with a developmental disability are at greater risk for Alzheimer's disease if they are older than 40 and have Down syndrome or come from a family with a history of Alzheimer's disease.
- Persons with Down syndrome appear to age more rapidly than other persons in the general population and thus are at greater risk for Alzheimer's disease than

are peers of similar age. Although only some 20 to 40 percent of adults over age 45 show the behavioral signs associated with symptoms of Alzheimer's disease, nearly all show the brain changes associated with Alzheimer's disease at death.

- A complete evaluation and several periodic reviews of behavioral changes are necessary to develop a diagnosis of Alzheimer's disease. These should include, at minimum, a comprehensive history, physical, neurologic and neuropsychiatric assessments, and a mental status exam.
- Persons who have Alzheimer's disease may be helped by care management programs. These help to maintain the person's highest level of functioning.
- To minimize confusion and agitation caused by dementia, changes in the residence and other familiar activities should be avoided.
- Staff, family and care providers should adapt the plan of care to reflect the person's diminishing abilities and focus on the person's remaining strengths.

FEEDBACK EXERCISE IV

1. Describe the symptoms Alzheimer's disease.
2. Describe the general course of Alzheimer's disease.
3. Explain why it is critical that a person showing signs of dementia have a complete medical workup.
4. Identify three risk factors for Alzheimer's disease for adults with developmental disabilities.
5. List behavioral symptoms of Alzheimer's dementia in adults with intellectual disabilities.
6. State five guidelines for care providers assisting with changes in behavior associated with Alzheimer's disease.

UNIT V: AGING AND CEREBRAL PALSY: CLINICAL CONCERNS

OBJECTIVES: After completing this unit, staff members will be able to:

Describe the implications of aging for persons with cerebral palsy.

Give guidelines for staff to help the older adult with cerebral palsy compensate for age related changes.

AGING AND LIFELONG CONDITIONS

In the United States, the national United Cerebral Palsy Associations, Inc. reports that although about 40 percent of persons with cerebral palsy are under 20 years of age, a substantial number of persons with cerebral palsy are now in their 50s and 60s and some are in their 70s and 80s. As in the general population, the life expectancy of persons with cerebral palsy is increasing and is, with the exception of those individuals who have the most severe degree of physical or mental impairment, approaching that of the general population.

Aging is generally assumed to follow the same sequence in all people. However, the rate by which these changes manifest themselves can vary widely. As in the general population, persons with lifelong conditions such as cerebral palsy experience growth, development, maintenance of function, and finally, loss of function.

WHAT IS CEREBRAL PALSY?

Cerebral palsy is a life-long motor dysfunction that resulted from a one-time injury to the immature brain in a fetus or an infant. As a result, central control of muscle function is adversely affected for the remainder of an individual's life. The brain injury is static; it is not progressive or regressive; that is, it can remain constant. These changes are due to biological, environmental and therapeutic influences on body structure and function.

Cerebral palsy is a condition, not a disease. Appropriate medical management and treatment, rehabilitative therapies, adaptive strategies, recreational activities and assistive technology enable persons with cerebral palsy to communicate and participate in regular educational programs, develop special interests and skills, find and hold jobs, live independently, marry and have children, retire and in general, to be active, productive members of their communities.

THE DISABILITY CONTINUUM

Adults with cerebral palsy form a varied population. Most adults with cerebral palsy work and participate in the normal activities of their community. In many instances, they do not need any special services to help them live their lives. In other cases, because of the nature or involvement of their disability, they may live in the community, and work and participate in community life, but need special supports or accommodations.

Cerebral palsy is a condition, defined by one's ability to control movement and posture. There are conditions associated with cerebral palsy that are also the result of the single injury to the immature brain and that may also determine or limit one's ability to function. Moreover, during a person's lifetime, there may be secondary conditions or age-related changes that may modify the person's functional status.

A primary disabling condition is one that is caused by a disease or disability, and is often manifested by a functional limitation. This functional limitation can be either physical or mental. Cerebral palsy is an example of a primary disabling condition.

There are *associated conditions*, those conditions that are a residual effect of the injury or pathology, and are linked to the primary disability. In persons with cerebral palsy, they can include seizures, intellectual disabilities, learning disabilities, and sensory problems such as hearing loss.

A secondary condition is a disease, injury, functional limitation, disability or handicap that occurs at any point during a person's life and is the result of the existence of the primary disabling condition. These conditions are seen more frequently than might be expected by chance.

The primary disabling condition can be a risk factor for any given secondary condition. In addition, the presence of the primary condition often alters the standard intervention for the prevention or treatment of the secondary condition. Moreover, the fact that a person is aging and has lived for many years with a disability may also put that person at risk for developing secondary conditions. In cerebral palsy, a pressure sore resulting from an ill-fitting wheelchair is a secondary condition.

Decreasing endurance with age in persons with cerebral palsy may also be a secondary condition, since there are only limited opportunities for those persons to exercise; but is also an effect of aging. In most instances, traditional intervention or prevention strategies to relieve the effects of aging or secondary conditions may need to be modified for persons with cerebral palsy.

HOW DOES AGING AFFECT PERSONS WITH CEREBRAL PALSY?

Adults with cerebral palsy age in the same way as the general population. There may be differences, however, in the way in which the consequences of the aging process are displayed.

The presence of motor impairments and other associated conditions may adversely interact with the aging process and may result in atypical adult development and aging. It is assumed that some decline will be due to the aging process, some to the effects of the primary disabling condition (including associated conditions) or secondary conditions, some to the interaction of the two, and others to unrelated or co-existing diseases.

The interaction of these factors (*aging, lifelong motor impairment and associated conditions*,

secondary conditions and age-related disease) may lead to decreased over-all function. There is little published information about the interaction of the aging process, the primary disabling condition, any associated conditions and secondary conditions, among adults with cerebral palsy. There is also not much information about the impact of commonly practiced interventions with persons with a disability over a lifetime.

It is difficult to establish which of these factors has the greatest impact and what can be done to slow or stop these changes. We do know, however, that environmental supports, such as assistive technologies, play an increasingly critical role in maintaining the balance among functional limitations associated with aging, life-long impairments, and independence for persons with cerebral palsy.

MUSCULOSKELETAL CONCERNS

Many adults with cerebral palsy indicate that musculoskeletal complaints are their most prominent concern. Motor function (mobility, strength, endurance) changes as a result of aging. However, when there is the co-occurrence of cerebral palsy, musculoskeletal problems may become more pervasive and often have an earlier onset than in the general population.

Changes in mobility and functioning:

Adults with cerebral palsy are at risk for having decreased function in their mobility as they age. They can expect some changes in muscle flexibility and it is likely that muscle strength and endurance will decline without routine maintenance activities, much as it does for their non-disabled peers. They can be at risk for falling and developing fractures or related problems. They may require more help with activities of daily living, in transfers, in assistance with personal hygiene, in dressing or with other every day requirements.

Often, spasticity seems to be more pronounced, frequently related to pain and fatigue. Knowing whether the changes are age related or secondary to a significant medical problem is often difficult.



A person with cerebral palsy may need more time to get around as he or she gets older. This may present the need for assistive devices, such as canes, walkers or wheelchairs. It may mean developing new ways of getting around, getting in and out of a bathtub, getting in and out of a car. It may also mean that the person needs to plan his or her daily activities in a different way. In order to adapt to these changes, it is important to know what adaptive equipment is available and how to procure it.

Pain and fatigue:

Musculoskeletal complaints can arise from a variety of causes. Commonly, pain is attributed to presumed “arthritis.” However, there often is no clinical evidence of arthritis. It is not known whether persons with cerebral palsy are at greater risk for developing age-related arthritis, or if they are prone to an earlier onset of this disease. Often the pain is related to soft tissue injuries in muscles, tendons, ligaments, or nerves. These conditions are likely to be the result of the way a person performs an activity and often may be the result of repetitive movements over time.

There is no information about the risks for developing pain or about preventing it, especially over a long period of time. Unfortunately for adults with cerebral palsy, in many instances their complaints about persistent pain are either ignored, or minimized (i.e., “You can expect this to occur and there is nothing we can do about it”).

Fatigue is a recurrent complaint for adults with cerebral palsy, particularly as they get older. As in the general population, fatigue may signal the onset of a general slowing down of the person; however, it may also signal the onset of a particular medical problem. Older persons with cerebral palsy may sometimes experience pain and fatigue together. Often this is ascribed to “depression” or psychosomatic issues.

There is little information about strategies to maintain endurance over a lifetime for an adult with cerebral palsy. Energy conservation should be considered when making choices regarding equipment, technology use, or exercise.

Osteoporosis and fractures:

Osteoporosis can be an ongoing problem for persons with cerebral palsy. As a secondary condition, it has been noted to occur early in life and is related to limited activity (particularly when there is a lack of weight bearing coupled with lack of muscle activity), poor nutrition, certain medications, or endocrine problems. In addition, older persons with cerebral palsy are also at risk for developing age-related osteoporosis.

The most significant complication of osteoporosis is fractures. Fractures resulting from secondary osteoporosis often involve a person’s limbs, and may be related to transfer lifting techniques or to injuries when an arm or leg may get caught when moving through a doorway in a wheelchair. Frequently the person or the care provider is not aware of the fracture and it is discovered by accident. Fractures resulting from age-related or post-menopausal osteoporosis are traditionally found at the spine or the hip in the general population. This is likely to be the site of injury for the older person with cerebral palsy as well.

Impact of previous treatment:

The long-term impact of the treatment that adults with cerebral palsy received in their younger years has not been studied. Concerns are based on two considerations. The first

involves a belief that vigorous applications of therapy (weight bearing on poorly aligned joints, stress to joints or muscle tendons from poorly controlled movements, and such) may have a long term deleterious effect. Also, long term effects of surgical interventions are being questioned. While no research yet has confirmed or disconfirmed these beliefs, there is anecdotal evidence supporting the notion that these practices bear further scrutiny.

The second belief concerns the cessation of therapies that may have been applied during the developmental period. As children, many adults with cerebral palsy, received physical or occupational therapy. As they reached late adolescence or young adulthood and made their own decisions about treatment, many decided to discontinue these therapies. Others may have been participating in routine therapies as a part of their school programs. As they aged out of these programs, usually by age 21, those services were discontinued, often without any concern or planning for maintenance or prevention programs. Lack of continuity of routine therapies bears further scrutiny.

Many experts in the field are beginning to question long held beliefs regarding intervention and the use of certain treatment modalities. It is imperative to take a hard look at those treatment modalities, how or whether they need to be modified, and the future implications of current treatment methods.

ORAL MOTOR PROBLEMS

The act of eating and swallowing is a complex physiological task. Some adults with cerebral palsy, especially those with severe impairments, experience great difficulties with this function. In these instances, they are also at risk for developing dental problems.

As the person ages, these problems tend to be aggravated by two related factors. The structure and overall health of dentition worsens, primarily as a consequence of disease and poor early dental care, and the amount of saliva produced diminishes as a result of aging (the amount of decrease may be exacerbated by various medications). This causes further problems because teeth are necessary to chew and saliva is needed to mix with food in order to facilitate swallowing. As a result, the already existing eating and swallowing problems get worse, and may result in a number of secondary conditions.

Eating and swallowing:

Persons with cerebral palsy may have mild to severe chewing, swallowing or choking problems. They may exhibit slow, delayed, or “unsafe” swallowing (or dysphagia), and may therefore choke or aspirate food or liquids. Problems with chewing and swallowing have an effect upon the type of food a person may choose to eat. These limited choices, in turn, may have an effect upon nutrition, weight maintenance, and overall health.

Dental problems/malocclusion:

Oral health problems increase with aging among persons with special dental care needs. Bruxism (or tooth grinding) can result in fractured teeth. Malocclusions (or problems with “bite”) are prevalent in adults with cerebral palsy due to abnormal muscle functioning, such

as facial grimacing, abnormal chewing and swallowing patterns, and tongue thrusting. In addition, although it is generally believed that temporal mandibular joint (TMJ) problems among adults with cerebral palsy are no more prevalent than among other adults, they usually occur more frequently among adults with malocclusion or poor dentition. Preventative and/or orthodontic therapy may have been difficult in adolescence due to noncompliance or other factors.

A common misperception is that the loss of teeth and poor oral health are normal by-products of the aging process for older persons with cerebral palsy. However, these problems are less related to normal aging and more a function of barriers to effective oral hygiene. Oral hygiene is often inadequate due to the lack of fine motor skills and lack of assistance by care givers. This can lead to dental plaque, halitosis, dental decay, infection and the early loss of one's teeth. However, most dental problems can be prevented with routine dental care and a good daily preventive program. Many adaptive aids are available and oral hygiene education for both the adult and, when appropriate, his or her caregiver is essential.

Dental professionals may need to be educated and trained in diagnosis and treatment planning for adults with cerebral palsy. Although certain barriers to care may still exist, modifications to offices and treatment protocols can make patient visits more efficient and successful.



GASTROINTESTINAL CONCERNS

As in the general population, some older persons with cerebral palsy report problems with heartburn, hemorrhoids and constipation.

Gastroesophageal reflux:

Gastroesophageal reflux is the backward flowing or return of the contents of the stomach or intestines. Reflux of stomach contents can be painful and a cause of discomfort. It can cause esophagitis (i.e., heartburn), gastritis, and ulcers. These problems can be exacerbated by certain medications (e.g., particularly anti-seizure and anti-inflammatory medications). These reflux problems can often result in vomiting, poor general nutrition, and retarded physical growth. One special problem related to gastroesophageal reflux is aspiration (which is fluid or food going into the airways). This can result in recurrent bouts with pneumonia, specially in persons who are severely physically disabled.

Constipation:

Constipation is a problem for many individuals with cerebral palsy, whether or not they are older. It is often related to insufficient dietary intake of fiber and fluids, as well as to a lack of routine physical movements to change intra-abdominal pressures. Certain medications can also aggravate the problem. Through diet modification, medication, or other bowel management strategies, regular bowel movements can be achieved.

Nutrition:



It is difficult to determine the energy and nutritional needs of a person with cerebral palsy, particularly among persons with severe impairments. Many adults with cerebral palsy expend large amounts of energy in maintaining their mobility. They are also at risk for nutrition-related problems due to many complex and interrelated physical, environmental, and psycho-social factors. Further, since some adults with cerebral palsy have few options for exercise, a steady weight gain can not be offset by a prescription for more physical activity. Concerns about nutrition, access to a balanced diet, and quality and quantity of food intake may take on special meaning when an individual may have difficulties in feeding him or herself, shopping for food, or determining nutritional needs.

UROLOGIC CONCERNS

Both men and women with cerebral palsy can have problems with urinary incontinence and retention. These urinary problems can be neurologically based, secondary to existing spasticity, or may result from a lack of appreciation of bladder fullness. Some women with cerebral palsy may also experience urinary problems related to their menstrual cycle.

As can be expected, lack of control of continence can also cause embarrassment. Loss of urinary control or changes in urinary function need to be more fully examined. Possible causes include: medication, spinal cord compression or other neurologic causes, urinary tract infection, or behavioral changes.

Besides biologic causes, there are other factors that may cause urinary problems. Among these factors are inability to void when needed because of unavailable or inaccessible toilet facilities, intake of very small or very large quantities of liquids, incomplete emptying of the bladder, infrequent voiding, and the use of external drainage devices. Among some adults with cerebral palsy and intellectual disabilities, a lack of cognitive awareness of fullness and a lack of any voluntary control may result in reflex voiding.

Yet, urinary continence can be addressed by a variety of methods. Urinary continence requires an ability to appreciate bladder fullness, to indicate the need to void or to have a voiding pattern established, to control the process of voiding, and to transfer to a commode with or without help. These are all areas where an individual can gain control and prevent incontinence.

REPRODUCTIVE CONCERNS

There is limited information about reproductive issues that are specific to adults with cerebral palsy. Both women and men with cerebral palsy report that they have genital and reproductive health concerns. Often, health care providers are not equipped to help them and in many instances the problems they experience are misdiagnosed or not properly treated. Some physicians may not be able to conduct a proper examination because of the individual's physical limitations (particularly, spasticity) or limited communication skills.

Reproductive concerns vary among men and women with cerebral palsy. Men express concerns about impotence and the physical means to meet their sexual needs. Women seem to express concerns about menopause and its manifestations. They are concerned about the additional physical problems that middle-age brings, such as emotional changes and changes in level of energy. There are also concerns over the physical implications of menopause, for example, difficulties with removing a sweater or other wrap during hot flashes.

A common concern among older adults is that symptoms and complaints are often difficult to communicate to health care providers and others. This may lead to frustration with the health care system and a tendency to avoid seeking treatment until health problems become serious. It can also lead to misdiagnoses of illnesses and secondary conditions when health practitioners cannot understand the individual's responses to questions.

PERSONAL EFFECTIVENESS CONCERNS

Adults with disabilities experience problems that reflect the normal aging process, as well as those unique to a life spent living with a disability. With the onset of middle age, many adults with cerebral palsy report changes in functional abilities that they did not anticipate. They had been led to believe that cerebral palsy is a non-progressive disorder and were not prepared for the fact that they can no longer easily do what they could do previously. These unexpected losses and impediments pose a new threat to their independence.

Many adults are now faced with having to develop acceptable solutions to continue day-to-day functioning. In turn, they may have difficulty coping with the age-associated changes that are complicated and perhaps accelerated by cerebral palsy. Many of these difficulties may become more of a problem when these changes interfere with their day-to-day social concerns, interpersonal relationships, employment, parenting, and other demands.

SUMMARY

Most adults with cerebral palsy are generally healthy, and, with greater attention to certain preventive health practices, could remain so as they age. As with other adults, responses to age-associated changes among adults with cerebral palsy vary from individual to individual. However, some adults experience age-related problems earlier than would be expected for their age.

- Many adults with cerebral palsy have problems with movement and other musculoskeletal functions. Motor function changes in mobility, strength and endurance occur during the maturation process.
- Oral health problems increase with aging.
- Nutrition concerns include an inability to maintain a balanced diet, and have control over the quality and quantity of food intake. Other significant issues among some adults include having difficulties in feeding oneself, shopping for food, and determining nutritional needs. These problems are often directly related to the individual's overall health status.
- With the onset of middle-age, many adults with cerebral palsy report changes in functional abilities that they did not anticipate.
- Health care providers are often not equipped to help older person with cerebral palsy and in many instances the problems they experience are misdiagnosed or not properly treated.

The information in this chapter was taken from the following report:

Turk, M. A., Overeynder, J.C., & Janicki, M.P. (Eds.). (1995). *Uncertain Future - Aging and Cerebral Palsy: Clinical Concerns*. Albany: New York State Developmental Disabilities Planning Council.

UNIT VI: MENTAL HEALTH ISSUES

OBJECTIVES: After completing this unit, staff members will be able to:

Differentiate between symptoms of mental illness and intellectual disabilities.

Define dementia, recognize the symptoms and list several treatment techniques

Define depression, recognize its indicators and list several treatment techniques.

Define schizophrenia and list some of its symptoms.

List at least 10 suggestions to help orientate the person to reality and reduce confusion. List at least 8 suggestions on how to deal with angry individuals. Use active listening to defuse anger and prevent behavior problems.

List a number of intervention techniques in dealing with problem behaviors.

INTELLECTUAL DISABILITIES AND MENTAL ILLNESS

The area of dual diagnosis and mental health of elderly persons is vast. Issues range from simple adjustment reactions and behavior problems to significant mental illnesses such as schizophrenia. Persons with developmental disabilities are more likely than others to experience mental health and/or adjustment problems. One reason for the higher risk of problems is the central nervous system deficits related to their disability. However, more important are environmental factors and the lack of learning opportunities. They may have less coping skills, more difficulty with interpersonal relationships, problems adjusting to changes in routine and difficulty communicating their feelings and needs.

Commonly listed symptoms of mental illness are low self-esteem, external orientation (being easily influenced by others), being very reactive, being moody, having difficulty expressing emotions, and the need for immediate gratification. They are symptoms frequently observed in persons with developmental disabilities. The following table should help differentiate between intellectual disabilities and mental illness.

DIFFERENCES BETWEEN INTELLECTUAL DISABILITIES AND MENTAL ILLNESS

	8	Mental Illness
Intellectual functioning	Subaverage	Unrelated to IQ
Areas of impairment	Impaired social adaptation in all areas of living	May lack social skills but be competent in other areas

	Intellectual disabilities	Mental Illness
Incidence	3 %	16-20%
Onset	At birth. Diagnosed before age 18.	Any age.
Permanence of condition	Permanent, but can be aided through training	Temporary and often reversible.
Behavior	Consistent and rational at individual's level of functioning. Erratic or violent behavior rare as caused only by low IQ.	Changeable, irrational behavior. Erratic or violent behavior is hallmark of some forms of mental illness.
Difficulties in adaptation	Secondary to limited intelligence.	Secondary to break with reality and/or emotional difficulties.

The team approach is vital when diagnosing mental health problems of people with developmental disabilities. The psychiatrist completes a physical and neurological examination and interprets data from psycho-logical evaluations. Direct staff provide objective data regarding the individual's behavior and symptoms. The report and recommendations should "make sense" based on all the information available.

Following are a few of the more common problems associated with elderly individuals with developmental disabilities.

DEMENTIA

Dementia is a progressive deterioration of mental functioning. While estimates suggest that about four percent (4%) of the general population suffers from dementia, thirteen to fourteen percent (13% - 14%) of people with developmental disabilities suffer from dementia.

Symptoms and Indicators

The causes and symptoms of dementia are varied. It can be caused by Alzheimer's disease, small strokes, malnutrition, drugs, disease, depression, syphilis, thyroid disorders, mercury bromide poisoning, encephalitis, anemia, and chronic alcoholism. The symptoms of dementia include disorientation, memory loss, unpredictability, decreased language skills, decreased judgment, decreased impulse control, increased hyperactivity, and personality changes.

Treatment

The treatment and prognosis for dementia varies. Various techniques such as psychotherapy, behavior management, medication, and social skills training are used. Some dementia is reversible when the underlying physiological cause is treatable, and some dementia such as Alzheimer's disease is not.

DEPRESSION*

Depression and its accompanying risk of suicide is the most common mental health disorder among the elderly. Between 20%-33% of the elderly are affected. Although there is little literature documenting the frequency of depression among the elderly persons with developmental disabilities, it is reasonable to suspect it is similar or higher than the frequency in the general population.

Causes:

Life Events. The most common causes of depression in the elderly are bereavement and grief for the many changes in life events. Those changes may include: a loss of identity due to retirement, change in living arrangements as health needs increase, loss of independence as vision and mobility change, and the adjustment to age-related physical changes that they are experiencing. Individually or in combination these losses may lead the older adult to become socially isolated. With this isolation, feelings of loneliness often occur. Your awareness of any major life losses will help you as you observe the older adult's mental/emotional status.

Other Illnesses. Long-term or sudden illnesses can bring on or aggravate depression. Strokes, certain types of cancer, diabetes, Parkinson's disease, and hormonal disorders are examples of illnesses that may be related to depressive disorders.



Medications. Some medicines cause depressive symptoms as side effects. Certain drugs used to treat high blood pressure and arthritis fall in this category. In addition, different drugs can interact in unforeseen ways when taken together. It is important that each doctor know all the different types and dosages of medicine being taken and discuss them with the patient.

Genetics and Family History. Depression runs in families. Children of depressed parents have a higher risk of being depressed themselves. Some people probably have a biological make-up that makes them particularly vulnerable.

Personality. Certain personalities - people with low self-esteem or who are very dependent on others - seem to be vulnerable to depression.

Indicators:

Everyone, at one time or another, has felt sad, gloomy, mournful, and/or down. These feelings are normal and may, for example, be experienced after losing a loved one, or losing a job. The feeling is consistent with the situation and does not, for any prolonged length of time, interrupt other aspects of life. But if the feelings persist with no lifting mood, the person may need professional treatment.

Indicators of depression are emotional, psychological, behavioral, and cognitive. Individuals affected by depression may experience persistent sadness, characterized by lack of interests in former activities, lack of emotion, boredom, fatigue, and inability to concentrate. Negative expectations may also be present. Behavioral deficits would include withdrawal, decreased sexual activity, slowed speech, neglect of hygiene, slumped posture, and forlorn expression. The person may have numerous complaints, crying, and self-injurious behavior. The person may suffer from sleep disturbances (sleep too much, sleep too little, or early morning awakening). The person may experience a change in eating habits or complain of gastrointestinal problems.



Depression and Other Illnesses:

Sometimes clinical depression can look like other illnesses with other symptoms such as headaches, backaches, joint pain, stomach problems, or other physical discomforts. Older people, when depressed, often speak of these problems rather than of feeling anxious, tired, or sad.

Some signs of depression, such as memory lapses and difficulty concentrating, can mimic Alzheimer's disease or other medical disorders. Similar symptoms may also result from other physical problems or from medications commonly used by older people. Therefore, for a proper diagnosis, it is important to have a thorough medical examination to rule out other disorders.

Treatment:

Depression in the elderly is often either not diagnosed, ignored, or viewed as a normal result of aging. The elderly are often reluctant to seek treatment, but another problem is that many therapists have negative attitudes towards treating the elderly. When the older person also has a developmental disability, treatment issues become even more complex.

However, if you are concerned that feelings of sadness, hopelessness and gloominess are constant and pervasive, referring the person to a qualified expert is appropriate. Proper treatment can often reverse or eliminate many of the symptoms mentioned. The longer

depression goes unrecognized and untreated, the outlook for recovery worsens, while those getting early diagnosis and treatment have the best outlook.

Treatment for depression may include meaningful activities, therapeutic opportunities to express guilt or loss, a supportive environment, and medication.

*Portions of this section were taken from: If You're Over 65 and Feeling Depressed..Treatment Brings New Hope, National Institute of Mental Health, US Department of Health and Human Services.

SCHIZOPHRENIA

Overall schizophrenia is characterized by an altered affective response, bizarre rituals, and interpersonal distancing. The symptoms of schizophrenia among individuals with mild intellectual disability are similar to those in the general population. The person with moderate intellectual disabilities and schizophrenia may experience withdrawal, fearfulness, paranoid ideas, sleep disorders, and hallucinations. It is difficult to make a diagnosis of schizophrenia for an individual with severe intellectual disability because of the difficulties determining if his/her inappropriate social and verbal interactions are the result of schizophrenia or intellectual disabilities.

TREATMENT FOR MENTAL ILLNESS

Reise (1993) in the Arc fact sheet Mental Illness in Persons with Mental Retardation stated that "Extraordinary progress has been made in the last 20 years with regard to the treatment of mental illnesses. However, these advances have been slow to be adapted for use with people with intellectual disabilities." He described the following treatment methods for individuals with intellectual disabilities and mental health disorders.

Psychopharmacology. There are many disorders that can be controlled or alleviated with medication. However, there has been a tendency in the past to over-medicate people with intellectual disabilities and not to carefully monitor the behavioral effects of medications. Even when used appropriately, medications are only part of an effective total treatment program.

Counseling/Psychotherapy. People with mild intellectual disabilities can benefit from counseling. Many individuals cope better when another person listens to their problems and provides social support and understanding.

Cognitive Therapy. This treatment teaches people with mild intellectual disabilities to recognize the situations in which they get into trouble and to develop alternative behavior and solutions to their problems. Although widely used with the general population, cognitive therapy has been adapted only recently for use with people with intellectual disabilities.

Behavior Management. This approach is widely used with people with intellectual disabilities and often leads to significant behavioral improvements.

Social Skills Training. This is a cost-effective, time-limited approach that often produces noticeable improvements in quality of life and interpersonal behavior. Individuals are gradually taught effective social interactions and appropriate social behavior.

Activity Therapy Music and Art Therapy. These are relatively cost-effective services that help build positive experiences and self-confidence.

PROMOTING MENTAL HEALTH

In the following pages of this unit you will find suggestions to help you deal more effectively with people experiencing behavioral or mental health problems (Gingold, 1985).

Reality Orientation

Reality orientation is being oriented to reality; knowing who you are, where you are, who the people around you are, and having an idea of the time, the day, the date, and the month of the year. Some elderly people suffer from moderate to severe memory loss causing confusion regarding time, place, and person.

The following suggestions may be helpful to orient the person to reality and reduce confusion:

1. Remind him/her often of who he/she is, the time, and the place. For example, "Mr. Jones, it's 12 o'clock. It's time for you to eat lunch in the dining room." Or, "It's two o'clock in the afternoon, Mrs. Smith. It's time to take your medication."
2. Talk distinctly and directly to the person, establish eye contact when possible.
3. Tactfully correct the person when he/she rambles in speech and/or action.
4. Explain and demonstrate new activities one step at a time.
5. Ask the person one question at a time.
6. Allow the person adequate time to answer questions.
7. Give clear and concise directions.
8. Be consistent.
9. Praise the person for relevant answers.
10. Teach the person to use props such as calendars, clocks, printed schedules to maintain a time orientation.

11. Provide a calm, friendly, supportive environment.
12. Have a set routine, getting up in the morning, activities, etc.
13. Provide environmental clues. This could include color coding doors and large numbers at eye level to assist in identification and help prevent confusion.
14. Give clear answers to questions or requests.
15. Expect the person to understand and whenever possible, to respond to the tone of your voice, attitude, touch, and eye contact.
16. Accentuate the positive.
17. Treat the person as a respected and dignified adult. Be supportive let the person know you care.
18. Be kind and polite while being matter-of-fact.
19. Observe and report changes in the individual's behavior to the appropriate staff.

Dealing with Anger

Handling anyone's anger can be puzzling and distressing. One problem when dealing with another person's anger is that the anger may cause angry feelings in us. We may not have been taught to deal with anger. We have been led to believe that anger is wrong and we should suppress it. Hence, it's easier to deal with an individual's anger if we understand that the goal is not to suppress or destroy it in the individual, but to help the individual handle anger in a more constructive fashion.

To that end we encourage the individual to express all their feelings. Our attempts should be directed toward showing the person acceptable ways to express feelings. Again, strong feelings shouldn't be denied, nor should angry outbursts be considered as a sign of serious problems.

Anger has many causes. The anger may be a defense to avoid painful feelings. It may be a release of anxious feelings about a situation over which the person has little control. It may be associated with feelings of failure, low self-esteem, isolation, dependency, depression, or sadness. Often anger and sadness are separated by a thin line. Remember, much of what the person has experienced as sadness may be expressed as anger.

When helping the angry individual, actions should be motivated by a need help him/her find safe ways to deal with anger. Alternatives must be taught. The following suggestions will help in dealing with an angry individual:

Reinforce desired behavior. Explain what behaviors you expect. As a caring individual, you will find countless opportunities during the day to make such comments as "I like the way you came to the meal without being asked", "I appreciate the way you hung up your clothes."

Deliberately ignore inappropriate behaviors which can be tolerated, i.e., "don't sweat the small stuff." This doesn't mean you ignore the person, just the inappropriate behavior. The ignoring is planned and consistent.

Provide physical outlets for releasing anger. It is important for the person to have opportunity for physical activity as allowed by medical condition.

Manipulate environment. Plan the environment to reduce problems. Stop a problem activity and try to substitute a different one. Many times rules and regulations are too confining and result in angry outbursts.

Use closeness and touching or allow for physical distance. Moving closer to a person may calm him/her down. However, there are times when we all want to be alone, or we are further aggravated by the close proximity of others. One's personal space should be respected.

Express interest in the person's activities. If a person has attempted to involve someone in his/her activities or accomplishments, and has been ignored or given the impression that it doesn't matter, the person may withdraw from social contacts and feel frustrated, unappreciated, and angered.

Show affection. Sometimes all the person needs is some attention.

Explain the situation. Help the person understand the cause of stressful situations. They may react properly if they understand the cause of the frustration.

Encourage the person to see his/her strengths as well as weaknesses. Help them build a positive self image.

Use prompts and rewards. Promises of future pleasures can be used to encourage appropriate behavior.

Use of physical restraint. On occasion, a person may lose physical control to the extent that he/she must be physically restrained and removed from the scene to help prevent him/her from hurting himself/herself or others. Staff must be properly trained prior to implementing physical restraint techniques. Follow your agency's policies and procedures regarding emergencies, or the behavior management program developed for the individual.

Set limits. Limitations established for individuals must be consistent with their legal rights. Once established, limits should be clear and consistently enforced.

Accept Anger Feelings. Let the person know that you accept angry feelings, but offer other ways to express them. Help teach the person to put his/her angry feelings into words or sign language rather than aggression. Help them learn to maintain control.

Active Listening

Active listening is one way to defuse anger and prevent behavior problems. It may be difficult for you to respond appropriately when a person confronts you with a problem or comes to you in need of understanding. You may respond by moralizing, preaching, teaching, advising, lecturing, warning, questioning, judging, analyzing, reassuring, or praising, and may block further communications.

Communication is a fifty-fifty proposition, and the ability to listen plays an equal role with the ability to voice thoughts. To truly hear what is being said and make a response that encourages the speaker to continue to share his/her feelings is a valuable skill that can be learned.

One way of enhancing communication is active listening. Active listening requires that the listener listen to the speaker and respond in one or more ways, by using personal statements, paraphrasing and questioning. Let's look at a couple of illustrations*:

Individual: What's it really like to die?
Listener: You have been thinking about death and what it will be like.
Individual: I'm so afraid of pain.
Listener: You think death will be painful, and it scares you.
Individual: I just wish the doctor would tell me exactly what is going on, so I know for sure.
Individual: I don't want to go to Mrs. Smith's house for the evening.
Listener: It seems to me that you and Mrs. Smith have some sort of problem.
Individual: I hate being with her. She doesn't look at me or speak to me.
Listener: You hate being ignored by others.
Individual: It makes me feel ugly and dumb.

*(From Geriatric Curriculum - Persistent Life Functions)

In each of the above exchanges, the listener proved he/she understood what the person said because he/she repeated the message back in his/her own words. Further communication was encouraged, because the listener made no judgment of the person. If the listener's feedback was inaccurate, because he/she misunderstood the person's message, the individual will almost always correct the listener.

The following are some guidelines to help you use active listening:

1. Know when to use active listening. Active listening is a technique to enable you to communicate your acceptance and empathy. Use it only when you are

free enough from your own baggage to be effective. Don't use it when you own the problem or when you feel unaccepting.

2. Skill comes with practice. It takes practice to use active listening effectively. Active listening may feel awkward at first but with practice it will become natural.
3. Don't give up too quickly. It takes time for the person to realize you want to understand and you accept his/her problems and feelings.
4. You will not know the capabilities of people unless you give them the chance to solve their problems. Start with an attitude that the person can solve his/her own problems, and you will be surprised how his/her trust in you will grow.
5. Try other listening skills. Not every situation calls for active listening. Use it primarily when feelings are strong, and the individual's need for acceptance is apparent. Avoid pushing or imposing active listening. Listen for cues that the person doesn't really want to talk. When the person wants information, give it.
6. Don't expect the person to arrive at your preferred solution.

INTERVENTION TECHNIQUES FOR PROBLEM BEHAVIORS

There are times when you will deal with individuals having severe emotional problems. Working with a disturbed individual can exhaust you mentally, emotionally, and physically. Some suggestions to help you deal with some common problem behaviors are:

Delusional thoughts (expressing false beliefs):

1. Provide for an non-threatening atmosphere, gain trust.
2. Divert focus from the delusions to reality in a matter-of-fact way.
3. Don't respond to delusional statements. Ignore them. Limit confrontations.
4. Don't argue.
5. Express genuine interest in their welfare through your tone of voice and attitude.
6. Focus on feelings, rather than what is being said.

Socially withdrawn behavior:

1. Initiate some social interaction with the person, but don't force yourself. Don't assume you're a friend, but agree you are not strangers.
2. Don't let yourself feel hostile or rejected, because the person doesn't respond socially to you.
3. Your behavior towards the individual should be consistent. This will allow him/her to trust you. Be punctual, consistent and predictable, keep a set

- routine.
4. Be honest but sensitive to feelings.

Low self-esteem:

1. Structure opportunities for success.
2. Focus on strengths.
3. Don't require him/her to make a decision unless you are confident the decision will be correct.
4. Provide praise for acceptable, appropriate or positive behavior.

Suspicious paranoid behavior:

1. Gain trust by being friendly, consistent, reliable, predictable.
2. Don't punish for paranoid behavior, but focus on reality.
3. Avoid power struggles, involve person in planning their treatment.
4. Don't try to use touch or affection unless the person appears to want it.

Hysterical behavior (outbursts of excessive emotions such as crying; laughing without apparent reason):

1. Use a matter-of-fact approach to direct attention away from behavior.
2. Don't reinforce hysterical behavior.
3. Don't confront with symptoms.

In summary, there are some similarities when dealing with problem behaviors. They are:

1. **Be consistent - this provides predictability and security.**
2. **Gain the individual's trust. Try to establish support.**
3. **Don't punish or judge.**
4. **Reinforce appropriate behaviors, responses.**
5. **Avoid power struggles.**

FEEDBACK EXERCISE VI

1. What are some of the causes of dementia?
2. What are some causes of depression?
3. What are some of the indicators of depression?
4. List at least 5 suggestions which may be helpful to orient the person to reality and reduce confusion.
5. What are some of the causes of anger?
6. List at least five suggestions which may help you in dealing with angry individuals.
7. What is active listening and how can it be used to defuse anger and prevent behavior problems.
8. List the five principles you must have in mind in dealing with problem behaviors.
9. Indicate whether the following are mainly characteristics of intellectual disabilities (ID) or mental illness (MI). Use ID for intellectual disabilities and MI for mental illness.
 - A. _____ Subaverage intellectual functioning.
 - B. _____ Incidence in general population 16% - 20%.
 - C. _____ Onset at birth, diagnosed before age 18.
 - D. _____ Behavior is changeable and irrational.
 - E. _____ Incidence in general population is approximately 3%.
 - F. _____ The onset occurs at any age.
 - G. _____ Unrelated to intellectual functioning.
 - H. _____ The condition is temporary and often reversible.

MODULE III: LEGAL SERVICES

UNIT VII: RIGHTS

OBJECTIVES: After completing this unit, staff members will be able to:

Define habilitation.

Explain and provide examples of the right to communication/inter- action.

Define confidentiality and provide examples where the right to confidentiality may be violated.

Explain and provide examples of the right to make informed choices such as to accept or refuse treatment or services.

Understand and explain the right to be free from physical and chemical restraint.

Understand the right to accessible services and programs.

INTRODUCTION

In 1981, the North Dakota State Legislature passed into law what is commonly referred to as the "DD Bill of Rights." This piece of legislation, as well as litigation (Association for Retarded Citizens of North Dakota v. Sinner, et al) has resulted in sweeping changes with respect to treatment, services and habilitation for our citizens who have developmental disabilities. Central to the DD Bill of Rights is the definition of developmental disabilities listed in the first chapter of this training manual.

Individuals who have varying forms of developmental disabilities may lack the information and knowledge needed to advocate on their own behalf. This problem is further compounded by age. Unlike the typical elderly individual, people with developmental disabilities who are also elderly often lack the informal supports common to their non-disabled counterparts. These individuals have outlived their parents and often do not have children. Furthermore, social networks may be limited due to segregation and poor socialization and communication skills. Because of these characteristics, elderly individuals with developmental disabilities have had to rely on paid staff for assistance in advocacy and other supports needed to assist them in learning about and exercising their legal rights. If it is the intent of staff to uphold the principle of treating the individuals they serve with dignity and respect, as well as the pursuit of one's personal autonomy, then a thorough understanding of the legal rights of elderly people who have developmental disabilities is essential.



There are several similarities between "resident rights" for individuals residing in long term care facilities and the D.D. Bill of Rights for individuals who have developmental disabilities. The focus of this chapter will be to address the similarities and distinguish the differences between these state statutes and the subsequent legal rights effecting residents of long term care facilities who also have developmental disabilities.

PROTECTION UNDER THE LAW FOR RESIDENTS OF LONG TERM CARE FACILITIES WHO HAVE DEVELOPMENTAL DISABILITIES

The Right to Habilitation

All individuals with developmental disabilities have a legal right to habilitation. Habilitation refers to a process by which individuals with developmental disabilities are assisted in (a) acquiring and maintaining those life skills which enable the individual to cope more effectively with the demands of one's own person and environment; (b) raising the level of one's mental, physical and social functioning; and (c) giving each individual a realistic opportunity to improve one's condition. The habilitation process enhances the well-being of the individual, teaches skills, and increases the possibility that individuals will make progressively independent and responsible decisions about social behavior, personal relationships, job satisfaction and self reliance needed for daily living.

The right to habilitation implies the right to an appropriate individualized habilitation plan. Individuals with intellectual disabilities who have resided in nursing facilities for more than 30 months, who choose not to relocate, and are in need of habilitation and/or specialized services, must have individualized habilitation plans (IHPs) developed by interdisciplinary teams and based on functional, comprehensive assessments.

Although a plan of care is developed for each individual of a long term care facility, such plans are usually based on a medical model and, therefore, are limited to medical and rehabilitative areas such as medication/treatment regimens, restorative services, therapies and diet. The focus of an IHP is more comprehensive than a plan of care. That is, based on the definition of habilitation, the IHP may address, as appropriate: activities of daily living, employment/vocational training, recreation/leisure, self care, social/emotional skills, communication, sexuality, self advocacy, financial management and medical/medication issues, cognition, therapies, and diet/nutrition, etc. In accordance with the D.D. Bill of Rights, the contents of a habilitation plan must include:

1. Long Term Goals - long term outcomes that provide the framework upon which behavioral objectives are developed. Individuals can generally expect to achieve goals within five years.
2. Intermediate Behavioral Objectives - short range outcomes that describe the individual's behavior as a result of training. Objectives are generally expected

to be achieved within one year. They should be written using terminology which is specific, observable, and measurable.

3. Evaluation Procedures and Schedules - methods and timetables for evaluating individual progress based on goals and objectives. Schedules specify training times which reflect the normal rhythm of life for persons of that age.
4. Personnel - the plan documents the staff needed for the provision of services.
5. Dates of Initiation and Duration - the plan documents when each service/training program will begin and end.
6. Review of Guardianship - the plan documents team discussion regarding the need, if any, for protection of the individual through some level of guardianship.

Individualized habilitation plans should be developed by teams which consist of at least the individual for whom the plan is written, and a representative of the service provider facility. In addition, the team should also include persons who have worked or will work most closely with the individual, those who provide needed assessments and services, and the individual's family, guardian or advocate as appropriate.

Habilitation teams must ensure that a plan is developed and put into effect within 30 days of an individual's admission to a facility. While plans must be reviewed and updated by the habilitation team at least annually, a designated team member must also review the plan as it relates to the individual's progress on goals and objectives at least monthly.

The Right to Appropriate Treatment, Services, and Habilitation in the Least Restrictive Appropriate Setting

In the previous section, we reviewed the right to habilitation. In a related issue, habilitation, treatment, and services for individuals with developmental disabilities must be appropriate and provided in the least restrictive appropriate setting possible. In other words, through legislation and litigation it has been determined that the requirements of habilitation must be interfaced with the requirements of appropriateness in order for an individual to receive maximum benefit from a service or program. The "appropriateness" of treatment, services, and habilitation can best be measured through ensuring that the unique strengths and needs of individuals are being met. Guidelines which may assist staff in determining appropriateness are:

- The proposed skill/behavior to be taught should have immediate utility. It should produce something useful for the individual or be part of broader skill that does so.
- The proposed skill/behavior should have desirability. It should produce something the individual would likely choose.

- The proposed skill/behavior should be acquired in a social context. The acquisition of skills should result from interactions with more than a single, caregiving person.
- The proposed skill/behavior should be acquired in the actual physical setting in which it will ultimately be used.
- The proposed skill/behavior should have practicality for the individual. It should be needed and practiced with some regularity.
- The proposed skill/behavior should be age appropriate. The behavior should facilitate social integration.
- The proposed skill/behavior should be adaptable. The skill should be generalizable to other various settings and situations.

"Appropriateness" can also be applied to the setting or environment in which a proposed service is to take place. Services and programs should be administered in an environment that is the least restrictive but will meet the unique needs of the individual. Prior to expecting an individual to change his/her behavior, environments should be analyzed for appropriateness. Individuals could exhibit frustration as a result of high expectations placed on them, noise, overcrowding, a lack of social contacts, physical barriers, and many other factors.

The Right to Communication/Interaction

There are three primary methods of communicating and interacting with others: by mail, telephone or visitation.

Mail - All individuals of health care facilities have the right to private, unimpeded, uncensored communication by mail. It may be assumed that individuals with developmental disabilities cannot read and, therefore, should have their mail opened and read to them. However, in accordance with laws regarding privacy, authorization must be granted by the resident prior to opening and/or reading another person's mail.



Telephone - All individuals of health care facilities have the right to private, unimpeded, uncensored communication by telephone. With respect to individuals who have developmental disabilities, state law requires that if restrictions are placed on the use of facility telephones, the facility director should establish in writing reasonable times and places for the use of telephones, provided that an individual's ability to contact an attorney is not restricted. Any restrictions developed must be posted in the residential facility, and copies must be given to the individuals residing in the facility.

Visitation - The Bill of Rights for residents residing in health care facilities mandates the right of individuals to have private meetings and associations within the facility with

whomever the individual chooses. In addition, individuals who are married may share a room unless not medically advisable. The D.D. Bill of Rights also recognizes that individuals who have developmental disabilities have the right to reasonable opportunity to interact with the opposite sex.

The Right to Confidentiality

North Dakota law references the right to confidentiality in the treatment of personal and medical records for both individuals of health care facilities and people who have developmental disabilities. Because the law specifically states "personal and medical records," many interpret this to mean that documents contained within an individual's file may not be shared with others outside of the facility providing services to that individual.



Although this interpretation is correct, it is also possibly the least common means by which confidential information is inappropriately shared with others. A breach in confidentiality may also occur through the following:

- When other individuals (aside from those whose professional duties allow access to records) are allowed access to the personal or medical records of residents.
- When records are released to others outside of a facility without expressed written authorization of the individual or legally authorized substitute.
- When personal information is shared by word of mouth to other people, including staff, who do not provide services to an individual and therefore, do not "need to know."
- When personal information regarding an individual is shared by word of mouth amongst those who "need to know", but is overheard by others who do not "need to know."
- When personal information regarding an individual is shared with an individual's legal guardian, but the guardian's authority is limited to another area. (Ex: the guardian's authority is limited to major medical decisions, yet he/she receives information regarding his/her ward's residential status).

As a general rule, personal information of an individual, which includes medical records, should not be shared with others without proper authorization. Facility staff who are unsure as to whether authorization has been granted should check with their supervisor.

The Right To Accept or Refuse Treatment or Services

All individuals, regardless of age or disability, have the right to accept or refuse services with few exceptions. In addition, most individuals are allowed to withdraw consent at any time without admonishment. Unfortunately, people with developmental disabilities are often

considered to be incompetent and thus unworthy of the necessary information needed to make an informed decision. Unless deemed incompetent by a court of law, all persons are free to make decisions regarding their self. More specifically, state law stipulates that no person with a developmental disability may be presumed incompetent or deprived of any legal rights solely because of admission to or residence at an institution or facility.

These references to the law have implications for employees of health care facilities and individuals with developmental disabilities who reside there. Individuals should be provided with all of the necessary information prior to being expected to make an informed decision. Such information should include:

- the nature of the procedure, service or program;
- why the procedure, service or program is recommended;
- the expectations/responsibilities of the individual and facility;
- the risks and benefits associated with the procedure, service, or program;
- alternatives to the proposed procedure, service or program;
- an explanation of the implications of consent, refusal or withdrawal of their decision

For elderly individuals who have developmental disabilities, how information is presented may be just as important as what is presented. Information must be presented as clearly and concisely as possible, in a setting which allows for few distractions. It can be helpful to present information in a concrete rather than abstract manner. For example, being able to tour/visit a court room or long term care facility may assist an individual in understanding a particular situation. Pictures, demonstrations and other materials, where applicable, can aid individuals in understanding information needed toward making a sound decision.

As previously mentioned, all individuals must be afforded a full disclosure of facts prior to giving consent. The same can be true for any individual who has previously provided consent and later withdraws it. Again, in order to insure that decisions are made based on factual information, a full disclosure of facts, must be provided. In accordance with the D.D. Bill of Rights, facility directors must inform individuals of alternatives, as well as risks and consequences associated with the withdrawal or refusal of consent to generally accepted services. Individuals who reside in health care facilities also have the right to be notified by their attending physician of the medical consequences associated with such decisions.

The Right To Be Free From Physical and Chemical Restraint

At the national level, much attention has been directed at the use of physical and/or chemical restraint of individuals residing in long term care facilities. "Physical restraint" can be defined as: manual methods or mechanical devices that are intended to restrict the

movement or normal functioning of a portion of an individual's body. "Chemical restraint" can be defined as the use of medication in isolated, emergency situations to calm or sedate an agitated individual. State law places restrictions on the manner for which both physical and chemical restraint may be used as evidenced by the following:

Physical Restraint. Individual's residing in long term care facilities who have developmental disabilities may not be physically restrained unless an emergency exists or the restraint procedure is approved by the individual and his/her habilitation team. Facility staff may use only the minimum amount of restriction or intrusion necessary as a protective measure.

1. Emergencies

Emergencies are those situations in which an individual's behavior has or could place that individual or others in imminent danger of physical harm when such behavior reasonably could not have been anticipated. For individuals with developmental disabilities residing in long term care facilities, a physician must authorize and document the use of physical restraint for a limited amount of time only.

2. Habilitation Team

Outside of an emergency, an Individualized Habilitation Plan team may approve the use of physical procedures as part of a positive, approved behavior program, subject to the conditions for restricting legal rights. It must be emphasized that as a member of the habilitation team, the individual with the developmental disability or the individual's legally authorized substitute, reserves the right to approve or disapprove of such a plan.

Ethical and moral principles require that facilities prohibit or severely limit the use of restrictive procedures such as physical restraint. Physical restraint may not be used or threatened to be used for purposes of punishment, for the convenience of staff, as a substitute for rehabilitation or treatment, or for any other purpose not considered an emergency or part of an approved habilitation plan. Therefore, concerns may arise if physical restraint is inappropriately implemented for one of the above stated reasons or because of misinterpretation of what can constitute an "emergency" situation.

In order to appropriately implement physical restraint procedures, facilities should ensure that:

- policies and procedures define interventions that may be used
- staff who implement behavior intervention procedures receive competency based training

As a reactive technique, physical restraint does not address underlying issues such as inappropriate habilitation or facility staffing patterns. A thorough examination of these and other supports and services should be undertaken prior to attempts at modifying an

individual's behavior through restraint.



Chemical Restraint. The manner in which chemical restraint can and cannot be used is virtually identical to that of physical restraint. State law pertaining to the rights of individuals with developmental disabilities also emphasizes that should chemical restraint be authorized by a physician, it must be necessary and appropriate as an element of the service being received or as a treatment of any medical or physical condition in conformity with accepted standards for that treatment.

The Right To Accessible Services and Programs

As part of the Rehabilitation Act of 1973, Congress enacted Section 504, the first federal civil rights law protecting the rights of persons with handicaps. Section 504 provides that "no otherwise qualified handicapped individual in the United States shall, solely by reason of handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance." Coverage under Section 504 applies to:

- any person who has a physical or mental impairment (either permanent or temporary) which substantially limits a major life activity (ex: self care, mobility, vision, learning, etc.)
- any person who has a history of a physical or mental impairment
- any person who is perceived as having a physical or mental impairment

Nationwide, over 43,000 organizations are subject to Section 504 regulations. Among the services/organizations which must comply are:

Education:

- preschool, elementary, and secondary education
- postsecondary education
- vocational and adult education

Government:

- U.S. Postal Service
- City, county, state and federal programs

Health Care

- hospitals and clinics
- long term care facilities

Human Services

- housing assistance programs
- habilitation/rehabilitation programs
- economic assistance programs



- medical assistance programs

Actions prohibited by organizations/programs such as those listed above can be summarized as:

- 1) Denying opportunities to participate
- 2) Providing unequal opportunity
- 3) Providing less effective services, benefits or aids as that given to others
- 4) Providing separate or different aid, unless required to provide equally effective benefits
- 5) Limiting enjoyment of right, privilege, opportunity or advantage enjoyed by others
- 6) Denying opportunities to serve on planning/advisory boards

Most recently, the civil rights protections of individuals with disabilities gained even greater attention. On July 26, 1990, President Bush signed the "Americans with Disabilities Act" (Public Law 101-336). This piece of federal legislation provides individuals with disabilities the civil rights protections already provided to other individuals on the basis of race, sex, national origin, and religion.

In response to findings that 43,000,000 Americans have one or more physical or mental disabilities and often have no legal recourse to redress discrimination, Congress responded that the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self sufficiency. Major provisions of the ADA include the prohibition of discrimination by employers against individuals with disabilities in hiring or promotion if the person is otherwise qualified for the job; the provision of "reasonable accommodation" by employers to individuals with disabilities unless such accommodations provide undue hardship; the accessibility of new public transit buses ordered after August 26, 1990; the removal of physical barriers in existing facilities if removal is readily achievable; and the accessibility of all new construction in public accommodations. Provisions also address discrimination by governments and telecommunication devices.

COMPETENCE AND CONSENT

In accordance with state law, no one with a developmental disability may be presumed to be incompetent or deprived of any rights solely because of admission to or residence at an institution or facility. What does "competence" mean, and who decides whether one is competent or not? In the legal sense, "competence" refers to someone who is legally qualified to make decisions and choices. Thus, one can presume that the only place where incompetence can be proven is in a court of law. Much like the presumption of innocence in

criminal law, the presumption of competency is a legal doctrine that guarantees personal freedoms against unwarranted restrictions.

People who have developmental disabilities are often wrongfully considered incompetent without the benefit of a determination through a court of law. Although habilitative training, advice and adequate information provided at a level an individual can understand are all tools which can be used to assist an individual in understanding the issue at hand, one may find situations where these less restrictive options are overlooked.

- Providing training, advice or information to others is time consuming. Individuals may be expected to make decisions quickly; or such situations may not have been previously anticipated and therefore, it is perceived to be too late for training.
- It is anticipated that the individual, even if provided with training, information and/or advice, will make a "wrong" choice. (In establishing competency, the courts do not require a person to make unquestionably correct decisions. Rather, people with developmental disabilities, like all others, enjoy what courts have determined to be "the right to be wrong").

A determination of incompetency and the resulting restriction of free choice is permissible only when one's mental capacity presents a threat to one's best interest that is more serious than the harm of the restriction of free choice. Only a court of law is appointed with the duty to weigh the options of competence v. incompetence. Thus, unless determined incompetent, it must be presumed that all adults, regardless of disability, are free to make their own decisions and choices. For those who work with adults who have developmental disabilities, it becomes clear that consent must be obtained from any individual for whom incompetency has not been legally determined.

What is "consent"? Consent can best be defined as approval or permission for something proposed or done by another. The purpose behind obtaining another's consent is:

- to retain freedom of choice for the individual
- to permit individuals to exercise the right to self determination/ personal autonomy
- to reduce civil and criminal liability to charges of acting without prior consent

In order to assure that consent is appropriately obtained, a review of the elements of consent is discussed below.

1. Capacity - the present ability to acquire and maintain information; the ability to formulate judgment and express choices. (Exception: those under age 18 are automatically assumed legally incompetent to make certain decisions).
2. Information - how information is provided is as important as what is provided. Is the information designed to be fully understood by the individual? Does the information provided address the following?

- nature of the proposed activity/procedure
- the importance (Why should the proposed activity be done?)
- possible consequences of the proposed activity
- the risks, benefits and alternatives to the proposed activity
- the right of the individual to consent, refuse or withdraw consent at any time

3. Voluntariness - the ability to exercise free power of choice minus any element of force, deceit, coercion or undue influence. For individuals receiving services through developmental disability or long term care facilities, the most common method of obtaining consent for major decisions is through the individualized habilitation plan and/or care plan meeting. While it is necessary to obtain an individual's consent for issues affecting habilitative and medical services during the habilitation/care plan meeting, the element of voluntariness also suggests that force or undue influence may exist in such meetings.



Through the eyes of the individual, being surrounded (and outnumbered) by professional perceived as authority figures can be overwhelming.

To compensate for this, it is suggested that staff and the parent/guardian/advocate, as appropriate, each discuss and review applicable information (See #2) with the individual prior to these meetings in a non-coercive manner.

The means for obtaining consent become more formal and should be more closely scrutinized whenever a proposed activity or procedure:

1. Obliges an individual to incur significant RISK.
2. INTRUDES physically, psychologically or socially on an individual.
3. Has a potentially IRREVERSIBLE impact

To summarize, all people of our country, regardless of sex, race, religion or disability, have the right to the same personal freedoms, including the right to make choices and decisions about their self based on the provision of adequate and appropriate information. The 14th Amendment of the U.S. Constitution mandates that no one infringe on these personal freedoms without due process.

RESTRICTING LEGAL RIGHTS

No one may infringe upon another's legal rights without due process (proof that such action is necessary). The two most common methods of limiting or modifying the legal rights of people who have developmental disabilities are through the judicial system (guardianship proceedings) and the individualized habilitation plan meeting. Attempting to restrict or deny someone of their legal rights is a serious issue and should not be taken lightly. In this section, we will examine those issues which must be considered prior to any restriction of

legal rights.

Guardianship

Employees of developmental disabilities facilities and senior programs are usually familiar with the term "guardianship", and most likely know first hand of individuals who have guardians. Unfortunately, though, some people misunderstand the intent of guardianship and for whom guardianship may be appropriate. It should not be assumed that individuals need guardians solely because of old age or disability. Guardianship **may be appropriate** for people impaired by reason of mental illness, mental deficiency, physical illness or disability, or chemical dependency to the extent that a person lacks the capacity to make or communicate responsible decisions regarding their self, which may include endangerment of the person's health or safety. Therefore, the central issues surrounding guardianship are:

1. Once provided with all the information needed to make major decisions, is the individual able to understand the ramifications of his/her choice (regardless of whether others agree with that preferred choice)?
2. Is the individual able to communicate his or her wants and needs (whether verbally, or through pictures or gestures)?
3. Has the individual made decisions in the past which have had a significant negative impact on his or her own health or safety?

An unfavorable response to any of the above questions is still not enough justification for guardianship. New state law created in 1989 strongly emphasizes the concept of "least restrictiveness." Guardianship should be considered a last resort after other alternatives such as advice and support, habilitative training, community medical assistance/training and financial assistance/training are exhausted.

If guardianship is pursued, there are six areas for which a proposed guardian may have decision making authority over a proposed ward: **residence, education, medical treatment, legal affairs, vocation and finance.** Guardians may have decision making authority on behalf of their ward in all six areas listed above, whereas "**limited guardianship**" means a guardian's authority is limited to at least one of the six areas as determined by the court. The court order appointing a guardian and the letters of guardianship must specify the guardian's authority in each of these areas.

A third form of guardianship is "temporary." "**Temporary guardianship**" is fairly self-explanatory: a temporary guardian may be removed at any time, with the length of the guardianship not to exceed ninety days. Unlike the other two forms of guardianship, the appointment of a temporary guardian is not evidence of an individual's incapacity. The purpose of temporary guardianship is:

- to provide assistance to individuals in emergencies; or
- to replace previously appointed guardians who are not effectively performing their

duties where the courts find that the welfare of ward requires immediate action.

Every guardian must involve the ward, to the extent practicable, in making any decision regarding the ward's living arrangements, health care, and any other aspect of the ward's care. The guardian must ensure the ward's maximum personal freedom by using the least restrictive form of intervention. A guardian should only intervene when necessary for the safety of the ward or others.

Issues in which guardians may not make decisions on behalf of their wards without specific review of a court are:

- voting
- abortion
- sterilization
- psychosurgery
- experimental treatment
- admittance to a mental health facility, state institution or secured unit of a long term care facility for more than 45 days

The court may require a guardian to make written reports and accountings to the court. These are usually required annually, but the court may require more frequent reports or accountings.

The central issue of guardianship is the protection of rights: does the risk of (usually permanent) removal of one's rights and personal decision-making greatly outweigh the need for self determination and actualization? The seriousness of guardianship warrants a careful review of the issues at hand. The conclusion that an individual is incapacitated and in need of a guardian depends upon evidence of the actual functioning of the individual, not merely upon labels or cognitive abilities.

The Individualized Habilitation Plan Meeting

Any consideration toward restricting an individual from exercising his or her legal rights by an individualized habilitation planning team must be closely scrutinized. Teams do not have the authority to restrict or deny the exercise of most statutory rights specific to people who have developmental disabilities. Those rights for which habilitation teams have no authority include:

- rights issues which must be addressed by the court (Ex: the right to vote; the right to determine incompetence; the right to determine the need for psychosurgery, sterilization, medical behavioral/pharmacological research)
- rights issues which are constitutional in nature (Ex: the right to free exercise of religion, the right to be free from cruel or unusual punishment, the right to appropriate treatment/services/ habilitation, the right to the least restrictive means of receiving services).

In order to restrict a legal right, the following issues should be taken into consideration:

1. The “burden of proof” is on those who wish to restrict a right.
Individuals who have developmental disabilities do not need to “justify” or prove that they have legal rights. Rather, those who suggest that an individual's ability to exercise their rights should be limited should have just cause. The individual should benefit significantly more from the proposed restriction than if left to exercise their rights of their own free will.
2. Less restrictive means and alternatives to the proposed restriction have been exhausted.
Have all other less restrictive alternatives and options been considered and attempted? Prior to expecting an individual to change his or her behavior, what attempts have been made to modify the environment, supports and services? Why have all previous options failed? Did staff consistently and appropriately implement previous programs?
3. The proposed restriction identifies the expectations of both the individual and staff.
How will the restricted right be reinstated? Have the responsibilities of both the individual and staff been specifically identified? Are mechanisms in place for appropriate periodical review of any program(s) which incorporate a restriction of rights?
4. Due process procedures are followed.
Has the individual been guaranteed the right to be informed and to appeal decisions through an impartial body? Regardless of an appeal, are proposed rights restrictions brought before an impartial body for review, such as an ethics or human rights committee?
5. Appropriate consent has been obtained.
Was appropriate and adequate information provided to the individual, parent or guardian, as appropriate, so that a decision can be made? Do facility policies reflect the need for review and consent of others aside from the habilitation team (ex: administration, ethics/human rights committees, facility boards of directors)?

As one can see, several issues must be addressed prior to the approval of any rights restriction. Regardless of whether the mechanism for restriction is guardianship or the habilitation team, all persons involved must ensure that no one is denied the freedom to exercise their rights and determine their own destiny without just cause and due process.

BASIC RIGHTS OF OLDER PERSONS WITH DEVELOPMENTAL DISABILITIES

Dr. Paul Cotten, a leader in the area of work with older persons with developmental disabilities, has proposed in the book, *Aging and Rehabilitation: Advances in the State of the Art* (Springer, 1985), that States consider the following Bill of Rights:

The right to an adequate standard of living, economic security, and protective work.

The right to humane services designed to help one reach his or her fullest potential.

The right to live as independently as one is capable and reside in the community of one's choice, in as normal a manner as is possible.

The right to an array of services that is generally available to other older persons.

The right to retire "to something" rather than "from something."

The right to participate as a member of the community, having reciprocal interdependency.

The right to be considered a person and not merely "elderly" or "retarded."

The right to protected well-being, and to a qualified guardian, when required.

The right to be involved in setting one's own goals and making one's own decisions; and the right to fail if necessary.

The right to be romantic, not asexual.

The right to a positive future, having enough involvement with life to prevent a preoccupation with death.

The right to sufficient activity and attention to permit continued integrity of self, individual identity, and purpose.

The right to an interesting environment and lifestyle, with availability of sufficient mobility to provide a variety of surroundings.

The right to live and die with dignity.

CONCLUSION

Throughout much of our history, individuals with developmental disabilities have been denied the opportunity to exercise their civil and legal rights due to the devaluation and stigma placed in them by the rest of our society. Through the passage of these and other forms of legislation, it is the hope that individuals with disabilities will be recognized as equal citizens under the law.

FEEDBACK EXERCISE VII

1. What must be included in the habilitation plan according to the D.D. Bill of Rights?
2. What are some of the guidelines to be considered in determining appropriateness related to habilitation, treatment, and services?
3. List the three primary methods of communication and interaction and explain the rights of individuals with developmental disabilities related to these methods.
4. List at least three situations where the right to confidentiality is breached.
5. Before individuals with developmental disabilities accept or refuse treatment or services, they must be provided with all the necessary information. What kind of information should be provided?
6. Individuals with developmental disabilities have the right to be free from physical and chemical restraint. Briefly explain this right.
7. What are some of the provisions of the "Americans with Disabilities Act" signed by the President in 1990?
8. What does competence mean and who decides whether one is competent or not?
9. What are the two most common methods of limiting or modifying the legal rights of people with developmental disabilities.
10. List these six areas for which a proposed guardian may have decision making authority over a proposed ward.

UNIT VIII: ABUSE, NEGLECT AND EXPLOITATION

OBJECTIVES After completing this unit, staff members will be able to:

- List and explain major variables which increase the likelihood of mistreatment of people with disabilities who are older.
- Identify causes of abuse, neglect, and exploitation and provide ways of prevention.
- Define and provide examples of abuse, neglect and exploitation.
- Explain who should respond and where and how to report alleged abuse, neglect and exploitation.

INTRODUCTION

As employees in either the developmental disabilities system or the aging services system, staff must be familiar with the complex issues regarding abuse, neglect, and exploitation. Abuse appears to occur with greater frequency among older adults with disabilities than for older persons in the general population. Such abuse can be emotional, physical or sexual and should be brought “out of the closet” in order to eliminate the situations that cause persons with disabilities to be abused. Such abuse may also be the result of vulnerability of men and women with a disability, who because of either their physical condition or emotional fragility are particularly susceptible to unwarranted exploitation or mistreatment. Individuals with disabilities who are older are vulnerable to abuse, neglect and exploitation when the person is (Rood, 1993):

- dependent on others for care
- unable to physically leave the environment or situation
- unable to change the environment or situation
- unable to speak or be heard and take action alone
- socially or psychologically isolated without other alternatives

The degree of functional disability also influences the individual’s risk of victimization. Severely or profoundly impaired mental capacity, sensory (vision & hearing) impairments, communication impairments, chronic mental illness or severe behavior problems, and mobility impairments increase the individual’s vulnerability to abuse, neglect and exploitation.

The reasons why mistreatment of the elderly occurs varies. In fact, in any situation it is unlikely that a single factor is responsible for the mistreatment. However, researchers are able to offer some tentative findings as to why some individuals become abusive. Some explanations include (Rood, 1993):

- some caregivers grew up in abusive homes where they learned dysfunctional patterns of relating to others
- inability to cope with personal problems on the part of the caregiver
- anger stemming from a caregiver's perception of powerlessness about their situation
- lack of skills to be able provide care for another (passive neglect)

In dependent care situations both men and women (though it tends to be more prevalent among women) who are severely physically impaired and who are physically handled, abuse may take the form of touching, fondling, or other more blatant acts. Abuse may also take the form of constant intrusions, lack of privacy, and lack of sensitivity upon exposing the person during bathing and other general personal care routines. It may also result in depersonalization in care situations where the adult is treated as an object rather than respected as a person with a need for privacy.

Passive neglect is the most common type of mistreatment of the elderly. Douglass (1989) states, "In most situations, passive neglect is the tragic result of well-meaning family members, friends or other persons who assume the care of a frail and dependent older person but who are incapable of meeting that person's needs." Hopefully, through education, cooperation, and communication with family members, direct service staff, supervisors, administrators, board members, and concerned citizens we can prevent further victimization of vulnerable adults.

Self-neglect is also a significant problem, particularly among those older adults who have difficulties with mobility and physical control. Thus, difficulties with staying clean, getting good nutrition, and maintaining other hygienic and health features pose barriers to effective personal functioning. These problems are exacerbated when the individual is socially isolated or neglected by their family or other caregiver. These special circumstances that confront many adults with physical disabilities place them at risk for further health problems. One outcome of this type of self-neglect is that as the individual grows older, s/he may begin to fail in the ability to carry out tasks of everyday living, then denying that this is happening, resist contact with social service and other agencies.

NORTH DAKOTA STATUTES

Most often mistreatment does not occur when there are witnesses present. Staff must become alert to signs that abuse, neglect, exploitation is occurring in addition to the overt actions defined in the law. The staff member's responsibility is to report any suspected mistreatment of the older adult with disabilities. A partial list of signs that may indicate that the person is being victimized include (this list is not intended to be exhaustive):

Physical Appearance:

Burns (especially unusually located)	Decayed Teeth
Clustered bruises	Bed sores
Bruises that resemble an object	Lacerations
Unhealed sores/untreated injuries	Odor
Clothing inappropriate for weather, filthy, torn, wrong size, worn out	Rash
Untreated medical conditions	Sudden weight loss/gain
Over/under-medication	Incontinence

Behavior:

Recent or sudden changes in behavior
Unjustified fears/ suspicions
Unwillingness to talk
Unreasonable excuses

Financial Indicators:

Unusual activity in bank account with nothing to show
Payment of exorbitant prices for services, repairs, rent
Chronic failure to pay bills

Reporting Abuse, Neglect And Exploitation

In addition to following state law, you need to be familiar with your agency policy and procedure for reporting suspected neglect, abuse, or exploitation. Rood (1993) suggested that the following may be useful to include in your report:



- Statements made by the alleged victim; behavioral signs and physical indicators of mistreatment; statements or threats made by the alleged perpetrator; actions of omission that you observed; environmental conditions; frequency and/or patterns of these indicators; and actions you have already taken.
- Observable actions, exactly what a person actually did or did not do.
- Specific behaviors and descriptions of your observations.
- Document the facts as you witness them. The investigation will determine guilt or innocence.
- Remember that your report will be used during the investigation, and never report maliciously.

Investigations

It is only through in-depth fact finding or investigation procedures that a determination of abuse, neglect or exploitation can be made. Once a report of alleged abuse, neglect, or exploitation has been made, the agency must report to the Department of Human Services within eight hours of knowledge of the incident. An internal investigation of the incident will be conducted by the agency to:

- gather information in order to describe and explain an incident or event
- determine if an individual's legal rights have been violated
- determine strategies that will decrease the potential of future reoccurrence of the mistreatment

The Protection and Advocacy Project will review the findings and may conduct further investigations. Pursuant to state and federal laws, agencies such as the Protection and Advocacy Project have access to facility residents, staff, records or other information considered relevant to an investigation.

References

Douglass, R. (1989) Domestic Mistreatment of the Elderly - Towards Prevention. Washington, DC: American Association of Retired Persons.

Rood, L. (1993). Neglect & Abuse of People Who Are Vulnerable. Omaha: Value-Based Training & Technical Services.

FEEDBACK EXERCISE VIII

1. State at least five guidelines for reporting suspected abuse, neglect, or exploitation.
2. What is the purpose of investigations once a report of alleged abuse, neglect or exploitation has been made? List three reasons.

FEEDBACK EXERCISE I Answers

1. What are some reasons for the widely varying base age for defining old age among individuals with intellectual disabilities and other developmental disabilities? List at least three reasons.
 - a. Some individuals with intellectual disabilities begin to experience decline in behavioral capabilities in their 50s.
 - b. There is evidence of precocious physical aging (along with an increased incidence of Alzheimer's disease) among people with Down's Syndrome - a major sub group within the population of persons with intellectual disabilities
 - c. Persons with intellectual disabilities have historically had a shorter average lifespan than their same aged peers in the general public.
2. Name three factors which affect the accurate determination of the number of older Americans with intellectual disabilities.
 - a. The difficulty of distinguishing between older adults who have cognitive or functional impairments and older adults who have intellectual disabilities.
 - b. Disassociation of some older Americans from the formal intellectual disabilities service system (unknown group).
 - c. At old age, the lack of a need to label people by disability type to obtain services generally available to any other older person.
3. Compare the demographics of the aging population with the demographics of the population of individuals with developmental disabilities who are aging.

Older Persons: We can expect by the year 2010, 1 out of every 7 Americans will be elderly. When looking at the elderly in particular, not only are the numbers of people over the age of 65 increasing, but changes are also occurring in health status of this group. While some people are living longer, healthier, more active lives, increased life expectancy also brings with it new problems which must be addressed. The most common conditions are: arthritis (48%), hypertension (37%), hearing impairments (32%), heart disease (30%), orthopedic impairments (18%), and cataracts (17%).

Older Persons With Developmental Disabilities: It is estimated that the population of individuals age 60+ with intellectual disabilities/ developmental disabilities will nearly double to 332,900 by 2025 because of longevity and size of the post World War II "baby boom" generation born between 1946-1964. It is generally assumed that older adults with intellectual disabilities have more health impairments and functional limitations than younger adults. However, studies that have reported on the health status and functional limitations of different samples have yielded conflicting outcomes. There is evidence that some early loss of functional skills does occur in this population; however, the loss is variable and subject to influences such as level of impairment, health status, and length of institutionalization.

FEEDBACK EXERCISE II Answers

1. What is Normalization

Utilization of means which are as culturally normative as possible in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible

2. Define Social Role Valorization

Has as its primary goal the establishment and protection of positively valued social roles for people who are devalued by society or at the risk of devaluation

3. What three factors place an older person with developmental disabilities in “triple jeopardy”?

Age, Disability, Poverty

4. List and explain the five criteria presented in this Unit which must be present in programs in order to adhere to the Principle of Normalization.

1. Community presence
2. Community participation
3. Skill enhancement
4. Autonomy and empowerment
5. Status enhancement

5. What is the role of philosophy in service delivery?

Philosophy includes the expression of values, principles, or qualities considered desirable in dealing with older adults with developmental disabilities. Such principles are derived from the collected opinions of experts in the field and provide guidelines by which we may judge the quality of services which we provide.

6. Define the term “ageism”: Discrimination against the elderly simply because of their age.
7. Give an example of age appropriate treatment of an older person with a developmental disability. (Answers will vary, see the table in the chapter for a guide)
8. Define the developmental principle. Every person, no matter how severely handicapped, has the capacity to learn, grow, and develop throughout life.
9. Identify developmentally appropriate alternatives for active treatment of older persons with D.D.
- a. Adjusting to decreasing physical strength and health.
 - b. Adjustment to retirement and reduced income.
 - c. Adjusting to death of significant persons in one's life
 - d. Establishing an explicit affiliation with one's age group.
 - e. Adopting and adapting social roles in a flexible way
 - f. Establishing satisfactory physical living arrangements.

10. What does the term “individualization” mean in delivery of services to older adults?

A guiding philosophy of services to the aging is to assure that their provision supports the individualized and unique needs and capabilities of the older person.

FEEDBACK EXERCISE III Answers

1. What are some of the implications of hearing problems for the older person?
- a. Trouble understanding speech/distinguishing sounds.
 - b. Cannot hear background noises/ feel separated from the world.
 - c. May stop trying to communicate with others/become isolated and withdrawn.
 - d. Become suspicious of others/misdiagnosis of paranoia or behavioral/emotional problems.
2. How can staff members/professionals alleviate some of these hearing problems?
- a. Increase loudness, but don't shout.
 - b. Speak clearly and distinctly.
 - c. Limit background noise and distraction.
 - d. Speak to the person at a distance of 3 to 6 feet. Position yourself near good light so that you lip movements, facial expressions, and gestures may be seen clearly.
 - e. Face the person you are addressing, establish eye contact. Be sure they are attending to you.
 - f. If the listener does not understand what was said, rephrase the idea in short, simple sentences.
3. What are some changes that occur as a result of aging on the musculoskeletal system?
- a. decrease in muscle mass and strength by as much as 50%.
 - b. decrease in energy

- c. progressive bone loss after age 40
- d. changes in posture
- e. decrease in fluid that lubricates joints

4. What are some of the implications of the musculoskeletal deconditioning?

- a. Discomfort.
- b. Lack of mobility.
- c. Decreased activity.
- d. Fear of falling/difficulty with steps.

What can staff do to assist the person to continue to maintain independence while experiencing these changes?

- a. Follow the physician recommendations on applying heat or cold to the affected joints.
- b. Assist the person to maintain their appropriate weight
- c. Encourage low stress impact exercise program
- d. Use adaptive aids for activities of daily living.
- e. Work with physician to achieve pain treatment and control
- f. Physical therapy.

5. What are some of the changes in the respiratory system as a person ages?

- a. Lungs become less efficient because the lower parts collapse and size of airways decrease.
- b. Less movement of secretions in the system because of decreased ciliary action in lungs and airways.

6. What are some of the suggestions to alleviate cardiovascular problems?

- a. Decrease or eliminate smoking.
- b. Lose weight.
- c. Decrease sodium, alcohol, fat, and caffeine intake.
- d. Get adequate rest.
- e. Increase exercise.

7. What are some of the changes in the gastrointestinal (digestive) system as a result of aging?

- a. Loss of teeth (75% or less of older population has adequate dentures).
- b. Ability to smell decreases.
- c. Ability to taste food decreases.
- d. Decrease in saliva and gastric juice production.
- e. Difficulty in swallowing.
- f. Constipation
- g. Hemorrhoids

8. How can we assist individuals experiencing these changes?

- a. Provide soft, easy to chew foods.
- b. Ensure good dental hygiene.
- c. Serve small frequent attractive meals.
- d. Serve the large meal early in the day.
- e. Use a relaxed atmosphere.
- f. Increase liquids, fruits, vegetables, and grains.
- g. Increase exercise.
- h. Avoid foods with seeds (e.g. tomatoes).
- i. Refrain from regular use of enemas or laxatives.
- j. Consider texture and consistency of foods as needed.

9. Match the following causes/effects with the types of impairment in vision listed below.

- | | |
|---|--|
| <p><u>C</u> Words closer than 12" become difficult to read.</p> <p><u>D</u> Colors such as blue and violet, at the lower end of the color spectrum, are difficult to see because the eye's lens begin to yellow.</p> <p><u>A</u> Occurs when lens become opaque or clouded. When light hits the eye it produces a glare and reduced vision.</p> <p><u>F</u> Occurs in situations of low light. Higher degrees of illumination are needed.</p> | <p>A. Cataracts</p> <p>B. Irritation</p> <p>C. Presbyopia/ Farsightedness</p> <p>D. Change in color perception</p> <p>E. Decrease of sharpness of vision</p> |
|---|--|

B Can be due to tear gland producing too few or too many tears. Both situations are correctable.

10. Listed below are different kinds of beef. Put them in sequential order moving from highly textured beef to lower textured beef. Use numbers 1 - 5, one being the highest degree of textured and five the lowest degree of texture.

- | | | | |
|------|----------------------------|------|---------------------------------|
| A. 3 | Broiled or fried hamburger | D. 4 | Chopped meat in spaghetti sauce |
| B. 5 | Pureed or strained beef | E. 2 | Minute steak |
| C. 1 | Beef steak | | |

11. How can staff members/professionals help individuals compensate for some of these vision problems?

- Use bright contrasting colors around doors and steps.
- Avoid highly polished surfaces. This will allow for good illumination, yet limit the glare.
- Use bright illumination. This will help the person distinguish detail and colors.
- Limit the duration of "close work".
- Provide support in a new environment until the person has become accustomed to it and can easily find his/her way around.
- Provide support when walking (if needed).
- Use adaptive aids such as big numbered telephones, large print books, and magnifying glasses.
- Provide adequate handrails in stairwells and other areas where the person may need support.

12. What risks are associated with deteriorations of the sense of smell and the sense of touch?

Potential hazards associated with the deteriorations of the sense of smell include the inability to detect gas leakage and spoiled food. Reduced sensitivity makes the elderly more susceptible to burns, hypothermia, or hyperthermia.

13. What can staff do to assist individuals experiencing age related changes in their physical appearance?

- Assist them to avoid excess sun and wind.
- Encourage them to eat a balanced diet.
- Promote healthy self-concept through education and program objectives to increase the understanding of the aging process.
- Promote good grooming.
- Promote good skin care and use of creams and lotions that do not contain alcohol and perfume.

14. What changes occur in the genitourinary system as a result of aging and what are the implications of these changes?

- The capacity of the bladder diminishes increasing the frequency of urination. Weakening of muscles may create difficulty in the emptying of the bladder, making the older adult more susceptible to urinary tract infections.
- There is a slowing of the filtering process by the kidneys, which means that medicine will tend to concentrate more quickly in the bloodstream.
- Life changes such as childbirth, diseases that restrict mobility or affect cognitive skills, changes in muscle tone and bladder capacity, and medication side-effects cause urinary incontinence.
- Enlarged prostate may begin to impede urination and prevent the bladder from emptying causing infections and possible kidney damage.
- Menopause usually begins around 50 years of age.

15. Use the information in the module to argue for or against the statement: "I can't learn this because I'm too old!"

While there is a decrease in the number of neurons and the processing time required by older adults, research indicates that age alone does not affect the ability to learn and intellectual decline is minimal. Problems with memory can be reduced by using organizational strategies and allowing more time for recall of information.

16. Why are individuals discouraged from using sleep promoting drugs?

Sleep promoting drugs should be avoided because people develop a dependency or a tolerance to the drug, and people taking other medications risk the possibility of drug interactions. In addition, sleep medications may decrease rapid eye movement sleep and produce anxiety and nightmares. Lastly, because many elderly persons metabolize drugs more slowly than younger people the drugs may decrease alertness the next day.

17. What suggestions would you give an older person who is having difficulty sleeping?

- Limit naps.
- Promote regular habits. People should get up and go to bed at a similar time each day.

- c. Increase exercise, but not too vigorous or too close to bedtime.
- d. Use white noises (constant background noises i.e. fan) to mask distractions in the environment.
- e. Check room temperatures. Be sure it is cool.
- f. Provide a light snack before bedtime. Foods such as warm milk have a natural sleep enhancing chemical.
- g. Decrease caffeine and alcohol. Alcohol may initially enhance sleep, but it has rebound effect, as a result one awakes and is not able to get back to sleep.

FEEDBACK EXERCISE IV

1. Describe the symptoms Alzheimer's disease.

Symptoms of Alzheimer's disease include losses in language, recent memory, orientation, activities of daily living, and changes in personality.

2. Describe the general course of Alzheimer's disease.

Alzheimer's disease is a slowly progressive disorder that eventually leads to death. The first stage lasts up to five years. The initial symptoms which include some memory loss of recent events appear very gradually. The individual may experience difficulty in finding the right words to use and work performance may begin to deteriorate. Changes in behavior may start to become obvious. During the second stage, there may be distinct problems with language abilities and difficulty understanding directions or instructions. They often become easily disoriented, confused, and frustrated. Memory losses become even more pronounced and the person may lose self-care skills, including the ability to use the toilet (incontinence), exhibit severe changes in personality, and his/her social behavior may be marked by suspiciousness (paranoia) and delusions. These changes may last for up to about twelve years. In the terminal stage basic skills such as eating or drinking are forgotten. Persons affected require complete 24-hour care and often become bedridden and inactive. Because of this, they are at increased risk for any infection, especially pneumonia, and consequently are far more likely to die. These changes, leading to death, may last for three or more years.

3. Explain why it is critical that a person showing signs of dementia have a complete medical workup.

Many conditions that are treatable produce symptoms that are similar to Alzheimer's disease.

4. Identify three risk factors for Alzheimer's disease for adults with developmental disabilities.

Over the Age of 40 and have Down syndrome
History of head injury, especially severe or multiple injuries
Family history of Alzheimer's disease

5. List behavioral symptoms of Alzheimer's dementia in adults with intellectual disabilities.

(1) the development of seizure in previously unaffected individual, (2) changes in personality, (3) long periods of inactivity or apathy, (4) hyper-reflexivity, (5) loss of activity of daily living skills, (6) visual retention deficits, (7) loss of speech, (8) disorientation, (9) increase in stereotyped behavior, and (10) abnormal neurological signs.

6. State five guidelines for care providers to assist with changes in behavior associated with Alzheimer's disease.
 - a. Modify the individual's program or support plan to anticipate changing needs.
 - b. Monitor and document increased episodes of confusion, disorientation, or memory lapses to become more prepared as they occur in the future.
 - c. Inform staff, and family members of changes and strategies in the plan of care.
 - d. Emphasize maintaining abilities, particularly those affecting dignity (eg., toileting, eating), rather than trying to teach new skills
 - e. Keep changes in environment and daily routine to an absolute minimum
 - Simplify routines and reduce choices to minimize feelings of anxiety and frustration
 - Use patience and redirection, keep verbal requests simple and provide general supportive care
 - Maintain self awareness by using reminiscing and talking about past experiences
 - Help the person maintain his or her orientation. Try not to force him or her back to your reality, but also don't allow a move into a delusion that you may be inadvertently reinforcing
 - Reassure the person daily, even when there is no response
 - Try to understand the words and symbols the person is using in communicating. Be patient, and don't try to force the person to understand your means of communicating; adapt to his or hers.
 - Provide appropriate foods and liquids to maintain nutrition and hydration
 - Respond to suspicions and delusions with reassurance

- Consult a physician about medications
- Minimize toileting accidents by establishing a toileting routine.
- Convey affection and protection by a quiet voice and use touch for reassurance and praise.
- Provide a familiar and safe environment
- Maintain present level of independence by increasing staff supervision and prompts
- Seek to identify “triggers” that result in inappropriate or dangerous behavior and try to minimize the likelihood that they will occur in the future.

FEEDBACK EXERCISE V Answers

1. Describe the implications of aging for persons with cerebral palsy.

The presence of motor impairments and other associated conditions may adversely interact with the aging process and may result in atypical development and aging. Concerns have been identified in the following areas:

Musculoskeletal

- Changes in mobility and functioning
- Pain and fatigue
- Osteoporosis and fractures

Oral motor

- Eating and swallowing
- Dental problems/ malocclusion

Gastrointestinal concerns

- Gastroesophageal reflux
- Constipation
- Nutrition

Urinary Incontinence

Reproductive Concerns

Personal Effectiveness

2. Give four guidelines for staff to help the older adult with cerebral palsy compensate for age related changes.
 - Allow more time for the person to get around as he or she gets older.
 - The person may need to be assisted to plan his or her daily activities in a different way.
 - Know what assistive devices and types of adaptive equipment are available and how to procure it.
 - Adjust the amount of help with activities of daily living, in transfers, in assistance with personal hygiene, in dressing or with other every day requirements as needed.
 - Watch for indicators of pain and discomfort related to age-related changes
 - Assist the person to adjust their activity level to accommodate changes in energy.
 - Assist the person to maintain proper dental hygiene including regular visits to the dentist.
 - Take special care to meet nutritional needs.
 - Assist the person in their adjustment to age-associated changes.

FEEDBACK EXERCISE VI Answers

1. What are some of the causes of dementia?

Alzheimer disease, small strokes, malnutrition, drugs, disease, depression, syphilis, thyroid disorders, mercury bromide poisoning, encephalitis, anemia, chronic alcoholism

2. What are some causes of depression?

Bereavement, changes in life circumstances, other illnesses, medication side effects, genetics and family history, dependent personality or low-self esteem.

3. What are some of the indicators of depression?

Emotional - sadness, apathy, and boredom, negative expectation, fatigue.

Behavioral - withdrawal, decreased sexual activity, slowed speech, neglect of hygiene, crying, self injurious behaviors.

Cognitive - inability to concentrate, lack of interest in former activities, forlorn expression.

4. List at least 5 suggestions which may be helpful to orient the person to reality and reduce confusion.

1. Remind the person often of who they are, the time and the place.

2. Talk directly and distinctly to the person. Establish eye contact.
3. Explain and demonstrate new activities one step at a time.
4. Ask the person one question at a time.
5. Allow the person adequate time to answer questions.
 - Give clear and concise directions.
 - Be consistent.
 - Praise the person for relevant answers.
 - Provide a calm, friendly, supportive environment.
 - Give clear answers to questions or requests.
 - Accentuate the positive.
 - Be polite and kind while being matter of fact.

5. What are some of the causes of anger?

A defense to avoid painful feelings.

Release of anxious feelings about a situation over which the person has little control.

May be associated with feelings of sadness, failure, low self esteem, isolation, dependency, or depression.

6. List at least five suggestions which may help you in dealing with angry individuals.

1. Reinforce desired behaviors.
2. Deliberately ignore inappropriate behaviors.
3. Provide physical outlets.
4. Manipulate environments.
5. Use closeness and touching or allow for physical distances
 - express concern and interest
 - encourage the person
 - show affection
 - explain the situation
 - use prompts and rewards
 - set limits

7. What is active listening and how can it be used to defuse anger and prevent behavior problems?

Active listening requires that the listener listens to the speaker and responds in one or more ways, by using personal statements paraphrasing and questioning.

1. Know when to use active listening.
2. Skill comes with practice
3. Do not give up too quickly.
4. Allow individuals a chance to solve own problems.
5. Do not expect the person to arrive at your preferred solution

8. List the five principles you must have in mind in dealing with problem behaviors.

1. Be consistent.
2. Gain the individual's trust/try to establish support.
3. Do not punish or judge.
4. Reinforce appropriate behaviors/responses.
5. Avoid power struggles.

9. Indicate whether the following are mainly characteristics of intellectual disabilities (ID) or mental illness (MI). Use ID for intellectual disabilities and MI for Mental illness.

- A. ID Subaverage intellectual functioning.
- B. MI Incidence in general population 16% - 20%.
- C. ID Onset at birth, diagnosed before age 18.
- D. MI Behavior is changeable and irrational.
- E. ID Incidence in general population is approximately 3%.
- F. MI The onset occurs at any age.
- G. MI Unrelated to intellectual functioning.

H. MI The condition is temporary and often reversible.

FEEDBACK EXERCISE VII Answers

1. What must be included in the habilitation plan according to the D.D. Bill of Rights?

Long term goals; Intermediate behavioral objectives; Evaluation procedures & schedule; Personnel; Date of initiation & duration; Review of guardianship

2. What are some of the guidelines to be considered in determining appropriateness related to habilitation, treatment, and services?

- a. Proposed skill/behavior to be taught should have immediate use.
- b. Proposed skill/behavior should have desirability.
- c. Proposed skill should be acquired in a social context.
- d. Proposed skill should be acquired in actual physical setting it will be used and be adaptable to other settings.
- e. Proposed skill should be practical and age appropriate.

3. List the three primary methods of communication and interaction and explain the rights of individuals with developmental disabilities related to these methods.

Mail - Individuals have the right to private, unimpeded uncensored mail. Authorization to open mail and have it read can be granted only by that individual.

Telephone - Individuals have the right to unimpeded, uncensored communication by telephone. Any restrictions must be in writing and posted in residential facility and copies given to the residents.

Visitation - Individuals have the right to private meetings and associations with individuals in the facility with whomever they chooses. Also includes the right to reasonable opportunity to interact with the opposite sex.

4. List at least three situations where the right to confidentiality is breached.

- a. When other individuals (aside from those whose professional duties allow access to records) are allowed access to the records of residents.
- b. When personal information is shared by word of mouth to other people, including staff, who do not provide services to an individual and therefore do not need to know.
- c. When personal information is shared with an individual's legal guardian, but legal guardian's authority is limited to another area.

5. Before individuals with developmental disabilities accept or refuse treatment or services, they must be provided with all the necessary information. What kind of information should be provided?

- The nature of the procedure, service or program. - Why the procedure, service or program is recommended. - Expectations/responsibilities of individual and facility. - Risks and benefits associated with procedure, service, or program. - Alternative to proposed procedure, service, or program. - An explanation of the implications of consent, refusal, or withdrawal of their decision.

6. Individuals with developmental disabilities have the right to be free from physical and chemical restraint. Briefly explain this right.

Use of physical and/or chemical restraints may not be used unless an emergency exists or the restraint procedure is approved by the individual and his/her habilitation team. It must be necessary and appropriate as an element of the service being received or as a treatment of any medical or physical condition in conformity with accepted standards for that treatment.

7. What are some of the provisions of the "Americans with Disabilities Act" signed by the President in 1990s?

- Equality of opportunity, full participation, independent living, an economic self sufficiency.
- Prohibition of discrimination by employers against individuals with disabilities in hiring or promotions.
- Removal of physical barriers in exiting facilities - if removal is readily available.

- Accessibility of all new construction in public accommodations.
- Accessibility of new public transit buses ordered after August 26, 1990s.

8. What does competence mean and who decides whether one is competent or not?

Competence - refers to someone who is legally qualified to make decisions and choices.
Only a court of law is appointed with the duty to weigh the options of competence v. incompetence.

9. What are the two most common methods of limiting or modifying the legal rights of people with developmental disabilities.

a. Through judicial system (guardianship proceedings). b. Individualized habilitation plan meeting.

10. List the six areas for which a proposed guardian may have decision making authority over a proposed ward.

Residence; Education; Medical treatment; Legal affairs; Vocational; Finances

FEEDBACK EXERCISE VIII Answers

1. State at least five guidelines for reporting suspected abuse, neglect, or exploitation.
 - Include statements made by the alleged victim; behavioral signs and physical indicators of mistreatment; statements or threats made by the alleged perpetrator; actions of omission that you observed; environmental conditions; frequency and/or patterns of these indicators; and actions you have already taken.
 - Report observable actions, exactly what a person actually did or did not do.
 - Report specific behaviors and descriptions of your observations.
 - Just document the facts as you witness them.
 - Remember that your report will be used during the investigation, and never report maliciously.
2. What is the purpose of investigations once a report of alleged abuse, neglect or exploitation has been made? List three reasons.
 - a. To gather information in order to describe and explain an incident or event.
 - b. To determine if an individual's legal right have been violated.
 - c. To determine strategies that will decrease the potential of future reoccurrence of mistreatment.